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THE PATIENT'S VOICE

CENTRE
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ICCEC 2014

10TH INTERNATIONAL CONFERENCE FOR CLINICAL ETHICS CONSULTATION

PROGRAM & ABSTRACTS

April 24, 25, 26 2014
Paris Descartes University - Paris

Contents

Editorial

The **International Conferences on Clinical Ethics & Consultation (ICCEC)** Series was developed to address a growing international need for a collegial setting in which to focus exclusively on topics in the areas of clinical ethics and ethics consultation. Soon after their development in the United States and Canada, health care ethics committees (HECs) and ethics consultation services spread around the world. These developments, the co-founders of the series believed, required a more focused attention beyond that received within existing professional organizations or local or regional conferences.

Unlike bioethics which often deals with broad ethical issues of public policy suffused with deep conceptual and theoretical issues, clinical ethics and ethics consultation address mundane and practical challenges involving uncertainties, confusions or conflicts of value that arise in the course of patient care. The responsibility for the development of protocols and procedures, education about ethical questions, and assistance in interpretation of policies or the meaning of ethical concepts as well in addressing value questions and concerns arising in patient care are now routinely addressed by HECs and clinical ethics consultation services. These practical tasks occur within the healthcare organizations like hospitals, long-term, rehabilitation, and out-patient clinics themselves, not in bioethics centers or academic departments. The wide variety of contexts of care in the course of delivering multiple health care services make addressing ethical and value questions complex and innovative. The experiences and expertises developed should be shared and reflected upon and critically evaluated so that best practices can emerge and be used. We believe that an international forum was needed not only for exchanging the experiences and ideas of clinical ethicists, but to develop a space in which emerging research might be fostered in this important area of work.

ICCEC has been a collegial endeavor from its beginning without the encumbrance or support of formal organizational structures like professional societies. Its successes are largely due to the commitments and hard work that local organizing committees – like **our hosts in PARIS 2014** – and sponsoring organizations have provided in making possible an annual occurrence also documented in publications: http://clinical-ethics.org/publications.html. Many international colleagues have assisted in reviewing abstracts, chairing and organizing sessions; their participation has made these conferences a worthwhile endeavor, which we hope will continue to serve as a valuable international forum for the field of clinical ethics and consultation.

The ICCEC forum also serves as the breeding ground for the annual **Hans Joachim Schwager Award for Clinical Ethics. In 2013,** this Award has been celebrated for the first time: http://clinical-ethics.org/hans_joachim_schwager_award_ceremony.html .

The co-founders of ICCEC,

George J. AGICH

Stella REITER-THEIL

The ICCEC 2014

The ICCEC 2014 is the 10th edition of the Series founded by Stella Reiter-Theil and Georges Agich in 2004.

This year, the motto of the Conference is "The patient's voice". The patients' rights movement has shaken medical practice since the '70s. Laws have backed up a deep turn in common mentalities and patients' expectations, and have precipitated momentous changes in the organization of care and the doctor/patient relationship. This is true above all in Western countries, although patients' position in healthcare has also undergone important changes elsewhere. Patients express themselves more often today and intend their voice to be heard. They «give voice» to several values, desires, preferences, will, etc.—and they do so in a multifarious way: not all patients are competent but they all speak, verbally and non verbally. The patient's own perspective and life-experience have emerged as an essential element of the therapeutic relationship.

This transformation has resulted in part from the importance give to the principle of respect for patients' autonomy – as a ground for medical decisions, and has been politically useful to redress asymmetries in power and knowledge. To that extent the principle of respect for autonomy has attracted much intellectual attention and has been analyzed in all its dimensions and different facets. However, medical practices as they can be viewed through clinical ethics support services (CESS) still fall far short of what would be ideally required with respect to the central place that the patient deserves. This is also true within the CESS themselves: the patient and/or her proxies are not always given as much voice as it is given to health care professionals.

Although the voice of the patient is paramount, the issues surrounding it go well beyond the informed consent of competent patients. Indeed, sometimes the patient's voice is still disregarded. Sometimes it is too weak to be heard, or it is considered as illegitimate. Family members or other proxies may speak instead, or on behalf of the patient. Also, the patients' voice might come to be in competition with that of health care workers. Finally, the patients' voice today is also relayed by collective entities as communities and patients' associations. All these areas require not only practical and procedural solutions, but also careful conceptual distinctions and substantial ethical analyses.

The call for papers was built around those themes. We received a lot of proposals. The majority of them was accepted and will be presented during the Conference. They are gathered in this book of abstracts.

Our acknowledgments go to all authors and contributors. And also to all the invited speakers and chairs who have accepted our invitation to be part of the Conference.

We hope the three Conference days will be a good occasion for everyone to meet, exchange, engage in a constructive dialogue, and establish connections and networks.

We wish you a very fruitful ICCEC 2014.

In the behalf of the Scientific and Organizational Committee

Véronique FOURNIER,
President,
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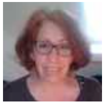

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Thursday, April 24, 2014

9.00 Welcome

Véronique FOURNIER, President, Scientific Committee, ICCEC 2014
Martin HIRSCH, General Director, Assistance Publique-Hôpitaux de Paris, Paris, France
Frédéric DARDEL, President, Paris Descartes University, Paris, France
Stella REITER-THEIL, co-founder ICCEC, Basel, Switzerland
➜ Amphi Farabœuf

9.30 Plenary Session

The ethics of Doctor Patient Relationship and Patient's Rights
Chair: **Bernard KOUCHNER,** Past Minister of Health, Paris, France
Speakers: **Etienne CANIARD,** President, Mutualité française, Paris, France
Martin WINCKLER, MD, Writer, Montréal, Canada
➜ Amphi Farabœuf

10.30 Coffee Break

11.00 Plenary Session

The patient's voice in the clinical ethics consultation
Chair: **Anne SLOWTHER,** MD, University of Warwick, United Kingdom
Speakers: **Mark AULISIO,** MD, Bioethicist, Ohio, USA
George AGICH, Philosopher, Bioethicist, Texas, USA
Véronique FOURNIER, MD, Centre d'éthique clinique, Paris, France
➜ Amphi Farabœuf

12.30 Lunch

Posters Session (1) ➜ Grand Hall

14.00 Parallel Session (1) ➜ Faculté de Médecine Paris Descartes

Room 1	Room 2	Room 3	Room 4	Room 5	Room 6	Room 7
The voiceless patient	**Patient's rights and the law**	**Patients' wishes at the « frontiers » of medicine**	**Advance directives: talking about one's own death?**	**Understanding the patient: hermeneutics or psychoanalysis?**	**Children's voice in clinical ethics**	**Questions of Ethics, a documentary from Anne GEORGET**
Chair: **Martin WINCKLER**	*Chair:* **Frédérique DREIFUSS-NETTER**	*Chair:* **Laurence BRUNET**	*Chair:* **Renzo PEGORARO**	*Chair:* **Danièle BRUN**	*Chair:* **Franco CARNEVALE**	*Chair:* **Gérard LÉVY and Séverine MATHIEU**
➜ Amphi Frezal	**➜ Amphi Farabœuf**	**➜ Amphi Portier**	**➜ Pavillon 1**	**➜ Pavillon 3**	**➜ Pavillon 4**	**➜ Salle 128**

15.30 Coffee Break

15.45 Parallel Session (2) ➜ Faculté de Médecine Paris Descartes

Room 1	Room 2	Room 3	Room 4	Room 5	Room 6
Narrative ethics	**The role of patients in health care education**	**The patient's role in Cess**	**Special needs and the rights of psychiatric patients**	**Medically assisted death: international perspectives**	**The role for autonomy in clinical ethics: an endless debate**
Chair: **Céline LEFÈVE**	*Chair:* **Thomas SANNIÉ**	*Chair:* **Sylvie EPELBOIN**	*Chair:* **Nicolas FOUREUR**	*Chair:* **Véronique FOURNIER**	*Chair:* **Robert BAKER**
➜ Amphi Frezal	**➜ Amphi Portier**	**➜ Pavillon 1**	**➜ Pavillon 3**	**➜ Amphi Farabœuf**	**➜ Pavillon 4**

17.45 Coffee Break

18.45 Key-note conference

The voice of inaudible patients : someone's else words
Hilde LINDEMANN, Philosopher, Michigan, USA
Chair: **Anne FAGOT-LARGEAULT,** philosopher, Honorary Professor, Collège de France, Paris, France
➜ Amphi Farabœuf

19.00 Cocktail reception

Schwager Price for Clinical Ethics ➜ Réfectoire des Cordeliers

Friday, April 25, 2014

9.00 **Plenary session**

Patient's values, healthcare professionals' values : which ethical conflicts?

Chair: **Mike PARKER,** Philosopher, Oxford University, United Kingdom

Speakers: **Franco CARNEVALE,** RN, PhD, Clinical Ethicist, McGill University, Canada
Daniel DEFERT, sociologist, Paris, France
John D. LANTOS, pediatrician, BiPast-president, ASBH, Kansas City, USA
Marta SPRANZI, PhD, Centre d'éthique clinique, Versailles University

➜ Amphi Farabœuf

10.30 **Coffee Break**

11.00 **Parallel Session (3)** **➜ Faculté de Médecine Paris Descartes**

Room 1	Room 2	Room 3	Room 4	Room 5	Room 6
Patient's voice in the French health care system	**Clinical ethics and psychiatry**	**Politically sensitive contexts and the patients' voice**	**Philosophical Foundations for Cess**	**Qualitative research : the patient's voice as methodological tool**	**Who best gives voice to the interests of the (future) child?**
Chair: **Claire COMPAGNON**	*Chair:* **Stella REITER-THEIL**	*Chair:* **Marie GAILLE**	*Chair:* **Georges AGICH**	*Chair:* **François DE SINGLY**	*Chair:* **John D. LANTOS**
➜ Amphi Farabœuf	**➜ Amphi Frezal**	**➜ Amphi Portier**	**➜ Pavillon 1**	**➜ Pavillon 3**	**➜ Pavillon 4**

13.00 **Lunch**

Posters session (2) **➜ Grand Hall**

14.00 **Parallel Session (4)** **➜ Faculté de Médecine Paris Descartes**

Room 1	Room 2	Room 3	Room 4	Room 5	Room 6	Room 7
Patients' values and religion	**Using gamete donation: to what ends?**	**The Voice of the Elderly in Nursing Homes**	**Proxies and families in clinical ethics**	**Healthcare professionals strategies for coping with ethical challenges**	**Considering adolescents : children or adults ?**	**Questions of Ethics, a documentary from Anne GEORGET**
Chair: **Jacques QUINTIN**	*Chair:* **Bertrand PULMAN**	*Chair:* **Reidun FORDE**	*Chair:* **Silviya ALEKSANDROVA-YANKULOVSKA**	*Chair:* **Pierre BOITTE**	*Chair:* **Florence VEBER**	*Chair:* **Denis BERTHIAU, François-Xavier GOUDOT**
➜ Amphi Portier	**➜ Amphi Frezal**	**➜ Amphi Farabœuf**	**➜ Pavillon 1**	**➜ Pavillon 3**	**➜ Pavillon 4**	**➜ Salle 128**

15.30 **Coffee Break**

15.45 **Plenary session**

Clinical Ethics and Justice : patients' interest versus society's interest

Chair: **Didier TABUTEAU,** Director, Public Health Department Foundation for Political Sciences, Paris, France

Speakers: **Marie GAILLE,** Philosopher, SPHERE, CNRS-Paris Diderot University, Paris, France
Aissatou TOURE, MD, Member, Ethics National Committee, Dakar, Senegal
Stella REITER-THEIL, Medical Ethics Professor, Co-founder ICCEC, Basel, Switzerland
Yann LE CAM, EURORDIS Chief Executive Officer, Vice Chairman EUCERD, Paris, France

➜ Amphi Farabœuf

17.30 **Key-note conference**

Which place for the patient's voice in the reflection of a National Ethics Committee?

Jean-Claude AMEISEN, President, Consultative National Ethics Committee (CCNE), Paris, France

With the participation of: **Claude RAMBAUD,** President, Collectif Interassociatif Sur la Santé (CISS), Paris, France

Chair: **Eric FAVEREAU,** journalist, Paris, France

➜ Amphi Farabœuf

Saturday, April 26, 2014

9.00	**Plenary session**	**Voices having hard time to make them listened in the health care system** *Chair:* **Dafna FEINHOLZ,** Chief of the Bioethics section, UNESCO, Paris, France *Speakers:* **Nadimpally SAROJINI,** social scientist, Director of SAMA (ressource group for women and health), New Delhi, India **Félicien MUNDAY,** MD, President, National Ethics Committee, Kinshasa, Congo **Debjani MUKHERJEE,** psychologist, bioethicist, Chicago, USA **Ryutaro TAKAHASHI,** geriatrician, Tokyo, Japan **Tim GREACEN,** user representative, Georges Pompidou European Hospital, Director of the Maison Blanche Research Unit, Paris, France **➜ Amphi Farabœuf**
11.00	**Coffee break**	
11.00	**Presentation of the project which has received the Schwager Award** *Chair:* **Stella REITER-THEIL**, Founding member of ICCEC, Professor of Medical Ethics, Basel University, Basel, Switzerland **➜ Amphi Farabœuf**	
11.30	**Plenary session**	**Selected Pieces, ICCEC 2014:** *Chair:* **Céline LEFÈVE,** Philosopher, Georges Canguilhem Center, SPHERE, Paris Diderot University, Paris, France *Speakers:* **Samia HURST,** MD, PhD, Bioethicist, Geneva, Switzerland **Sadek BELOUCIF,** MD, Avicenne Hospital , AP-HP, Paris, France **Bert MOLEWIJK,** RN, Bioethicist, Amsterdam, Netherland **Anne-Marie MOULIN,** MD, Philosopher, CNRS-INSERM, Paris, France **➜ Amphi Farabœuf**
12.30	**Closing session**	**Véronique FOURNIER,** president, scientific committee ICCEC 2014 **Georges AGICH,** Cofounder ICCEC, Texas, USA **Rosamond RHODES** and **ROBERT BAKER,** ICCEC 2015, New-York, USA **Jean-Loup SALZMANN,** President, Conférence des Présidents d'Universités, President, University of Paris Nord, Paris, France **Marisol TOURAINE,** French Minister for Social Affairs and Health Care, Paris, France (to be confirmed) **➜ Amphi Farabœuf**

Thursday, April 24, 2014 morning

9h00-9h30

Welcome: Véronique FOURNIER, President, Scientific Committee, ICCEC 2014

Opening session: Martin HIRSCH, General Director, Assistance Publique-Hôpitaux de Paris, Paris, France
Frédéric DARDEL, President, Paris Descartes University, Paris, France
Stella REITER-THEIL, Co-founder ICCEC, Basel, Switzerland

9h30-10h30 PLENARY SESSION:

The ethics of Doctor Patient Relationship and Patients' Rights

Chair: **Bernard KOUCHNER,** Past Minister of Health, Paris, France

Patients' collective voice: an ethical and political necessity

Etienne CANIARD, President, Mutualité française, Paris, France

In France, the patient's voice was brought out by a political patients' rights movement. This movement successfully lobbied for legislation like the 2002 law, the hallmark of which was that it granted individual patients the right to direct access to their medical records. As a result, a collective movement served to gain an individual right. But the same law was also an opportunity to enshrine a certain number of collective healthcare-system users' rights. It also paved the way for dialogue and openness that has been greatly beneficial to the whole society. Healthcare associations went to work, and formed an inter-association collective called the CISS (Collectif Inter-Associatif Sur la Santé: Inter-Association Collective on Healthcare). Gradually, patient representatives were integrated in the decision-making bodies at various levels of the healthcare system. Training programs for these representatives were set up. These representatives then participated in drafting new recommendations on a number of questions: for example, on how a diagnosis of cancer should be announced, or a study by the High Authority on Healthcare of how to fight everyday maltreatment at the reception desk of a public hospital emergency room. However, the enthusiasm of the early years has been drying up. Ten years down the road, we are forced to observe that the role and voice of the patients' movement has been fading away in recent years. I shall point out the most obvious signs of this lack of interest, and consider various hypotheses that might explain it. The possible reasons, the easiest to cite, are political or economic in nature. Going beyond this question, the most disturbing trend is the weakening of the collective patients' voice and its distance from the initial source of inspiration in ethics. At the time, the chief concern that carried the law was less the need for a redistribution of rights than the urgency to acknowledge that the patient deserved greater respect as a whole person: the primary individual concerned by the disease. Yet in the intervening years, claims have drifted towards new rights. There is a great temptation to oppose the rights of some and the duties of others, and vice-versa. As a result, the debate is often reduced to a mere test of strength that is harmful to everyone. Far from opposing individual and collective patients' voices, we should probably recognize that the individual dimension bears the principal source of ethical inspiration providing grounds and meaning for collective claims. We must learn to return to this source constantly, which is exactly what the clinical ethics approach invites us to do.

The patient's voice in the ethics of healthcare profesionnals

Martin WINCKLER, MD, Writer, Montréal, Canada

Caregiving is about sharing, collaboration (working together) and cooperation (acting together). It is not about power, for a simple reason: a caregiver is not the patient's boss, nor her parent, nor her spiritual adviser. A caregiver is a hired professional who focuses her knowledge and know-how on a specific goal : help the patient overcome, or live with, her condition. The ethical guidelines governing caregiving are numerous, complex, often conflicting. Caregivers are often tempted to bypass them « for the benefit of the patient » - therefore, to take the power back. The only way to avoid these transgressions is to constantly listen to the patient's voice ; for she, and only she, can say what she wants to do with her life.

10h30-11h00 COFFEE BREAK

11h00-12h30 PLENARY SESSION:

The patient's voice in the clinical ethics consultation

Chair: **Anne SLOWTHER,** MD, University of Warwick, United Kingdom

Ethics Facilitation: The Voice of the Patient in the ASBH "Ethics Facilitation" Approach

Mark AULISIO, MD, Bioethicist, Ohio, USA

This presentation will draw out the implications of the American Society for Bioethics and Humanities' (ASBH) "Ethics Facilitation" approach to ethics consultation for patient involvement in ethics consultation and, ultimately, for ensuring that the patient's voice is heard. This will be done, first, by explicating the relevant textual evidence from Core Competencies for Health Care Ethics Consultation (1998, 2011) and then, second, by considering what the central normative concerns of the Ethics Facilitation approach mean for "hearing the patient's voice" in actual clinical cases. The latter will be illustrated by applying an Ethics Facilitation approach to a series of cases drawn from the presenter's experience in clinical ethics consultation. Cases to be discussed may include:

- A family's request to withhold diagnosis of terminal cancer from an adult patient with decision capacity
- A physician's decision to withdraw potentially life-saving antibiotic treatment from an adult patient with decision capacity due to "bad" (non-adherent) patient behavior
- A spouse's demand that ventilator support be withdrawn from her temporarily incapacitated husband , who was otherwise expected to make a full recovery
- An adult son's inability to "make this decision" resulting in the provision of aggressive care at the end of life to a terminally ill incapacitated cancer patient contrary to the patient's wishes

It will be argued that each of the cases discussed involved the risk of the patient's voice being drowned out by other competing (louder) voices – a risk averted, at least in part, through Ethics Facilitation as the presenter interprets it.

Engaged Ethics Consultation

George AGICH, Philosopher, Bioethicist, Texas, USA

In this lecture, I advocate an engaged model of ethics consultation, one in which the ethics consultant functions much like medical consultants who are, or can be, actively involved in patient care. I discuss what the concept of engagement in patient care involves for ethics consultation and argue that two features are hallmarks of an engaged form of ethics consultation. First, the ethics consultant functions as an independent professional. By independent I mean that the ethics consultant should rely, whenever possible, on information that is primary and not information about the problem that is pre-given, predefined, or pre-interpreted by others. This requirement implies that the ethics consultant does a first-hand assessment of the situation including an independent review of the patient chart, direct interview of relevant parties involved in the case, especially the bedside care providers, and requests missing information. The ethics consultant thus functions in a way that allows the ethics consultant to assess the situation and/or problem(s) as initially presented, and then reframes or redefines the problem list insofar as possible in terms of the best available evidence and not just the evidence most conveniently available. Where multiple problems exist, the prioritization should be done by the ethics consultant. Although the primary actions will be carried out by other health care team members, the ethics consultant should accept responsibility for assuring that the services provided and recommended actions are carried out thoroughly. Second, the engaged ethics consultant is active in patient care and is seen as a member, though episodic, of the health care team. Although many commentators regard the ethics consultant as an advisor external to patient care processes, I will argue that in many instances ethics consultants are justifiably engaged in the delivery of services that require their active involvement in patient care. Their activities include direct communication orally and in writing, primarily in chart notes, with the health care team and through direct communication with the patient and/or patient's family. When the case calls for team or family conferences, they are and should be active participants, though not necessarily as the convener of the conferences. Conceptualizing the engaged nature of the activities of the ethics consultant as a component of patient care importantly helps to clarify the responsibilities associated with the various stages of doing ethics consultation. The implications of this model are most evident for setting expectations about how the ethics consultant should assess the ethical problem or issue on which they are asked to consult, how they should communicate with the patient and patient's family and health professionals involved in the case, and how they should comport themselves in resolving the problem or questions that they have identified. On the view that I will defend, ethics consultation involves a definable set of activities and responsibilities that ideally define the scope of practice of ethics consultation services. As I will argue, ethics consultation is best seen as a part of patient care; hence, it is engaged. Ethics consultation is not a set of activities that can be primarily conducted from the sidelines through educational discussions or dialogues with health care professionals or through academic analysis of pre-given ethical questions or problems. These observations have the important implication that the activities which define engaged ethics consultation thus demarcate the reasonable expectations, and hence competences, that individuals providing ethics consultation services should meet.

The Clinical Ethics Consultation : The "commitment" model

Véronique FOURNIER, MD, Bioethicist, Centre d'éthique clinique, Cochin Hospital, AP-HP, Paris, France

In France, everything is political. Moreover, one of the characteristics of the French society might be the importance given, whatever the topic is, to the 'collective' or 'societal' dimension of it, in opposition to the strict 'individualistic' one. That might be the reason why the model of Clinical Ethics Consultation (Cess) that we developed in Cochin Hospital (Paris) functions as it functions. At all the steps of the process, we act as a team and not as a single consultant, differently as the major part of other Cess. In this presentation, I will show how we practically do ethics consultations and argue that our collective way of practicing the consultation makes the patient's voice have greater chances to be heard. In addition, I will defend why we propose to call our model of Cess the "commitment" model, namely in relation to our collective and multidisciplinary focus. Even if the term of "commitment" can be used to characterize several features of our model, I will focus here on one meaning of "commitment": pursuing and implementing in a coherent and continuous way the same shared goal, i.e. to enhance the chances that the patient's voice be given the paramount place it deserves. We maintain that "commitment " to this main goal plays itself out at three different levels. First, at the consult level, the fact of acting as a team rather than a single consultant offers a plurality of attentive and sensitive ears that amplify the chances for the patient to be understood and his arguments to be heeded to. As Aulisio says, the risk in ethics cases is that the patient's voice will be drowned out by other competing (louder) voices. A collegial and multidisciplinary approach helps to prevent this risk. Furthermore, during the case conference organized for debating the case at stake, the diversity of the ethics group again favours a more thorough consideration of all arguments, not only the medical ones but also the patient's ones, underlying the decision to be made. The reasoning is progressively enriched by the different contributions that are brought up during the ethics deliberation by all the diverse people attending the conference. Each of them reacts with his own professional as well as personal background. The job is not only to give an advice to the ethics consult team, but to try to elaborate a sort of democratically debated opinion that might be useful for all the protagonists concerned by the decision. I will show how it works through specific examples. This will allow me to better highlight some similarities and differences with other models of Cess. Finally, I will show how our enterprise of clinical ethics is conducive to making the patients' voice louder at yet a third and public level. We consider ourselves as having an obligation to actively contribute to the public debates organized about some of the main issues on which we are regularly called on, i.e. end of life issues, access to reproductive technologies or the medical ethical issues raised by the ageing. Here, it is not the voice of a single patient that we give echo to, but the voices of all the people we meet at the occasion of our ethics consults or clinical ethics research projects. We thus help the society at large to better understand how patients' expectations and societal values change, according to what can be observed on the clinical ground.

12h30-14h00 LUNCH - POSTERS SESSION (1)

Thursday, April 24, 2014 afternoon

14h00-15h30 PARALLEL SESSION (1)

ROOM 1: The voiceless patient

Chair: **Martin WINCKLER,** MD, Writer, Montreal, Canada

What Does it Mean to Advocate for Vulnerable Patients in Ethics Consultation? Who Should Do It?

Tracy BRAZG, Phd Student, Clinical Bioethics Fellow, University of Washington, Seattle Children's hospital, Seattle, USA

Patient advocacy is a commitment shared by a number of healthcare professions to address and counter the power imbalances inherent in the healthcare system. Ensuring that stories are told and understood is a central feature of patient advocacy and especially important for vulnerable patients. Over the past several years the topic of patient advocacy has received increased attention in the bioethics literature, where the conversation has focused largely on the roles and boundaries of clinical ethics consultants (CECs) as patient advocates (i.e., Should CECs play the role of patient advocate?) (Rasmussen, 2012; Schwartz, 2002; Stell, 2009). While it is important for the profession to articulate CECs responsibilities and boundaries with regard to patient advocacy, the primary purpose of this presentation is not to address the question of whether or not CECs should play the role of patient advocate. Who is best situated to play the role of patient advocate is likely dependent on the context of the particular case. Rather, we argue that it is necessary to take a step back to better articulate what is meant by patient advocacy in the context of healthcare ethics consultation (HCEC), and to systematically pay attention to the particular circumstance when it is most needed. We argue that patient advocacy has not been clearly defined in the bioethics literature, and that the core condition of vulnerability has been largely glossed over. The topic deserves special attention as an intervention for circumstances involving vulnerable or disenfranchised patients involved in HCEC. Engaging in ethical deliberation through HCEC is a process of constructing and critically analyzing diverse and often divergent narratives. Among other tasks, CECs and members of ethics committees are responsible for weaving together a series of stories and considering the best way of moving forward towards resolution (Rubin, 2002). The centrality of storytelling in ethical deliberation has been informed by the method of Narrative Ethics. The narrative approach requires the recognition that there is not a single "right" story, and that all stakeholders must be given the opportunity to share their perspectives on equal footing (Rubin, 2002). As the practice of HCEC moves toward a greater reliance on narrative, it is important to critically examine the ways in which stakeholders' stories are constructed (Rubin, 2002). This means paying attention to whose voices are systematically included in the process of HCEC, and also paying attention to how stories are received by ethics consultants and other healthcare professionals. One unexamined assumption of Narrative Ethics is that when given the opportunity, all stakeholders have an equal opportunity to share their "side" of the story. The reality is that those who are most vulnerable and disenfranchised in the healthcare system may not be able and/or given the opportunity to share their stories in ways that are understandable to those who most need to hear them. The presentation will provide a conceptualization of patient advocacy as it relates to HCEC. By applying our concept to two cases, we will clarify what it means to advocate for the vulnerable in HCEC, how to recognize when patient advocacy is a necessary element of HCEC, and how to determine which member of the healthcare team is best-suited to take on the role of patient advocate in the resolution of ethical dilemmas.

Encouraging care professionals to listen to the voice of the person with dementia when collecting information instead of focusing solely on the words of the caregiver

Ito MIO, Researcher, Geriatric Nursing, Tokyo Metropolitan Institute of Gerontology, Tokyo, Japan

Japan is currently the oldest country in the world. As people grow older, the population with dementia also increases. The decreasing availability of adult children and increases in the aging population have made the role of caregiving spouses essential. Caring for a spouse with dementia in a limited space can be stressful, increasing feelings of burden. Stressed caregivers easily focus on the difficulty at the point of "now". Then caregivers tend not to talk to care receivers which often makes their relationships worse. In Japan, Long Term Care Insurance started in 2000, and home care professionals help support the elder's life. But frequently care professionals mostly talk to family caregivers to collect information. When that happens, the person with dementia has fewer opportunities to join any conversation even while they are using home care services. In our research "The Couple's life story approach", we had discussions with a care manager about this approach, and realized that some home care professionals have difficulty in communicating with persons with dementia. In home settings, there is not much chance to learn from other care staff'. In this report, the care manager was included in the couples' life story interview, and we discussed the possibility of using this dyadic approach in home care settings. The couples' life story approach is to interview couples in which one spouse has dementia using a life story approach to help them jointly reconstruct the story of their marriage. During the joint interviews, their photographs are used to stimulate conversation and memories between the couple. Couples were recruited from home care services. We used a life story board to conduct interviews with couples over 4 sessions. Couples selected a maximum of ten pictures before each session. In this case, the care manager participated in 2-4 sessions. The care manager and the researcher met after each session to review the process. Findings: In this case, the husband in the couple had Alzheimer's disease, and his MMSE score was 11. Both husband and wife were over 80. They lived with their son's family. During 3 session of the couples' life story approach, the care manager always sat next to the caregiver. In the second session, the first time the care manager participated,, the care manager mostly talked to the caregiver, and the researcher mostly talked to the care recipient. After the second session, the care manager said, "I didn't know he could speak that much. I never tried to wait for him to talk. I feel so sorry about that." In the second session, the care manager sat next to the caregiver again but she didn't talk to the caregiver as much. The care manager tried to listen to the care recipient, but sometimes repeated the question to the caregiver to clarify what he said. When the care manager asked the wife questions just after talking to him, the husband seemed confused. After this session, the care manager and researcher discussed the interaction and the care manager realized that she was used to trying to get the true story. In the last session, the care manager just listened and sometimes repeated his words while nodding. The husband then started to talk to the care manager too. The couple's life story approach promotes understanding of their married lives together before and after dementia occurred. But if care professionals concentrate on grasping the facts, they will mostly talk to caregivers and the person with dementia will feel isolated even though the care manager is a guest in their house. Care professionals need to understand how the clients perceive the situation not only verbally, but also visually. If the person with dementia can have triggers for his memory, it will be easier to remember the past. If the person with dementia can talk about the situation as he sees it, the assessment of care professionals might change. The goal of this project is to understand the importance of listening to the voices of persons with dementia as well as to the caregivers.

A voice for the unexpressive patient: enactment of personhood in the intensive care unit

Gitte Hansses KOKSVIK, Phd candidate, Social anthropology, philosophy, Norwegian University of Science and Technology (NTNU), Trondheim, Norway

In this paper, I reflect on patients who have no voice, my example being unconscious or low-level consciousness patients in intensive care. In the intensive care unit (ICU) a great part of patients fit into this category. A multitude of apparatus and tubes go in and out of patient's bodies administering medicines, palliating organ function and removing waste from the body, creating a new, hybrid form of life between the organic and the inorganic. The very condition of intensive care breaches any conventional understanding of the modern ideal of patient autonomy. Here, human expressivity is suppressed, both by illness and by the treatment itself. Indeed, sometimes the expression of the patient is the graphs and lines appearing on the monitor, and values on a paper that tell us how the person is "doing". Nursing staff undertake a range of practices as a measure of relating to the patients as persons: they talk to them, use their names and explain every procedure before embarking upon it, regardless of whether or not the patient can hear or understand. They do this because the person is believed to be "in there somewhere". A journal initiative for the patients has also been launched. Kept by the nurses, they describe treatment and the patient's state as well as mundane affairs and relevant societal news. Discharged intensive care patients often cannot remember their stay in the unit; days, perhaps even weeks of their lives are missing to them. These journals are intended to restore some of this void by letting them know, after the fact, who was there with them and what happened. Nevertheless, knowing the patient in intensive care usually refers to knowing their symptoms and physiological facts. The possibility for objectivation is imminent. Yet there is another side to this, occasionally expressed by care workers: care of the inexpressive body as a response to a "pure", human solicitation for help. Human vulnerability exposed. In a society obsessed with autonomy, one often equates personhood and dignity with doing, and the notion of a meaningful life is linked to self-expressivity. Giving a voice to inexpressive patients such as many in intensive care, would perhaps involve a different mindset. Notions of dignity become important. In virtue of what do unconscious intensive care patients have dignity? Accepting a human condition of resilience and vulnerability, we can overcome the dichotomous relationship between on the one hand the passive body-as-known and on the other the actively knowing subject. In a perspective borrowed from Annemarie Mol we see ontology not as a given, but as something which is shaped and brought to existence in day-to-day socio-material practices. In which ways can personhood and dignity of the inexpressive be enacted through care?

Representing the Voices of Unrepresented Persons

Leslie KUHNEL, Center Director/Ethics Officer, Healthcare Ethicist, Alegent Creighton Health, Omaha, Nebraska, USA

Hearing the voices of the most vulnerable members of our community can be one of the most challenging questions posed to ethics consultation teams. A notable area of vulnerability is that experienced by persons who do not have the capacity to make their own decisions and for whom there a legally-recognized surrogate decision-maker. Such persons are often referred to as "unrepresented (or "unbefriended") persons". Reasons for the circumstances of unrepresentation are varied, and can include any number of the following factors: • a decreasing availability of proximate support persons as families expand across the country; • limited access to long term care facilities and mental health care services when consents for treatment cannot be given; • ever-more complex qualification and reporting requirements for those willing to serve in court-appointed representative roles; and • weak or absent infrastructures for providing representation for vulnerable adult persons. Given these complex factors, unrepresented persons and their care providers often find themselves caught in the limbo created between the desire to advance the patient to a more appropriate setting for care and the absence of recognized surrogate decision-maker to move the process forward. Often unrepresented persons linger for days, weeks and months in hospitals unable to be safely discharged to a next level of care where they can move forward with their treatment plan. This frequently traps care teams, organizations and unrepresented persons themselves in a strange sort of liminal state between "what is now" and "what comes next". While in this state, unrepresented persons are at greater risk for acquiring additional illnesses and for delaying the implementation of preferred treatment plans; care providers are more likely to experience moral distress; and organizations struggle with strains on limited resources (emergency room and acute mental healthcare beds, for example) as unrepresented persons remain in acute care setting for extended periods of time. For these reasons, it could be argued that in response to the Patient Rights movement of the 70's the dramatic shift away from medical paternalism and its reliance on the "best interest standard" for decision-making, and towards an almost-absolute reliance on patient autonomy as exercised through first-person or substituted-judgment decision-making standards has resulted in a reluctance to uphold that basic obligation of medicine to "first, do no harm". Drawing upon the experiences of my own organization, this presentation will: • explore the ethics dilemmas related to the treatment of unrepresented persons; • identify the moral distress experienced by care team members and others involved in the care of unrepresented persons; • describe one approach to decision-making on behalf of unrepresented persons; • introduce a patient-centered decision-making tool that can be implemented in the context of unrepresented persons; and • engage participants in creative dialogue about similar experiences and possible approaches.

ROOM 2: Patients' rights and the law

Chair: **Frédérique DREIFUSS-NETTER,** Law Professor, member of the Comité Consultatif National d'Ethique (CCNE), Paris, France

Clinical ethics, the patient's voice, and legal obligations: Is the law obligated to support the patient's voice?

Denis BERTHIAU, Law Professor, Paris Descartes University, Paris, France

The French "patients' rights" law of March 4, 2002 was designed to promote the patient's voice and give weight to his decisions. It is part of an effort to establish a more egalitarian relationship between patients and doctors, who are sometimes perceived as being too paternalistic. More generally, it is part of a trend to grant a more active role to the individual in an effort to establish more fairness in many other human relationships; for example, the provider/consumer relationship. French legislators voted to impose legal obligations on clinical staff. Should they fail to comply, their liability is engaged. The most talked-about obligations are the obligation to inform, and the obligation to respect refusal of treatment. Written into the 2002 law, they were reinforced by the law dated April 22, 2005, on the end of life and patients' rights. The clinical ethics method is an appropriate tool for assessing the effectiveness of the legislator's decisions and the means employed to achieve the law's goal. By instituting a battery of obligations, have we found the best way to ensure that the patient's voice will be heard? This is the question we will study in our talk, on the basis of examples related to informed refusal of treatment, on the one hand and, on the other, a study of advance directives drafted by persons over the age of 75, carried out by the Center for Clinical Ethics at Hôpital Cochin.

When the patient's voice is expressed electronically: What are the issues? How can the voice be channeled?

Marie-Eve BOUTHILLIER, Manager, Clinical Ethics Unit, Centre de santé et de services sociaux, Laval, Canada

In the past several months, many of the questions submitted to our Clinical Ethics consultancy unit (SCEC) have concerned the use of new communications technologies. For example, some users have asked for permission to record follow-up sessions with mental health clinic and oncology staff members. Other users have decided to install webcams in long-term residential treatment clinics, in order to keep an eye on the bed of a family member who is hospitalized there, without necessarily informing the supervisory staff. In a third case, a patient used his iPad to take photographs and videos of patients who were unconscious, without their knowledge, during treatment episodes. These situations raise a number of ethical issues and questions. Problems and questions • Is it acceptable to install a camera (hidden or not), or to use other electronic means of monitoring, recording, or communicating with healthcare staff? If so, in what context? Should a distinction be made between communication and monitoring? Is the use of these technological resources in the best interest of the patient, whether or not he is conscious? • Is it ethically justifiable for the family of an unconscious or incompetent patient to monitor his bed with a camera? Does it give them a better guarantee of the quality of clinical procedures (fewer incidents, for example, or quicker responses)? Is such a measure liable to harm the therapeutic trust and alliance relationship? Does it change the way staff members behave (for example, will they feel less human warmth toward the patient, for fear that it will be misinterpreted out of context? Will they feel fearful of being spied upon? Will they refuse to provide care?)? Will the audio or video capture end up online? • In Quebec and Canada, the legal status of the use of a camera and other technological means is still vague in many respects. Although the interception of private communication is a violation of the Criminal Code, we doubt that this law will be applied to the use of a camera at a hospital. This said, no law specifically forbids it. Thus, it is not illegal to install a camera, but the act might be construed as an offense justifying legal proceedings and carrying a fine. It would therefore seem that the use of a camera must respect certain restrictions in order to comply with the law. The following questions are pertinent: In what context or contexts can a camera or other technological means be used? What restrictions should be applied to this use? Does labor law permit the installation by a third party of cameras to monitor caregivers? How do we define patients' rights? Caregivers' rights? How can fundamental rights be reconciled in order to avoid possible violations of dignity, image, privacy, and security? Goals and methodology: The goal of our talk is to present three points: 1. Ethical issues associated with new communications technologies; 2. Our ethical analysis of the question; 3. The framework we suggest as the grounds for an official ruling. We shall rely on case studies that were submitted to our unit, and explain the process we undertook in our ethical analysis and the limitations we believe are necessary as a framework for these practices.

Patient's autonomy in (criminal) law and practice

Katrin FORSTNER, phd candidate, Criminal Law, University of Vienna, Vienna, Austria

Nowadays, medical staff is often confronted with patients who do not agree to medically indicated treatment of first choice or completely refuse treatment. From a criminal legal perspective, only the patient's will is in the centre of the decision making process, e.g. in the German-speaking countries. Therefore, medical staff, in general, has to act according to the patients' will. After exhaustive information on the treatment recommended by the doctor, the patient can give his informed consent to the treatment – or refuse it. Doctors and other parties from the health-care sector acting against the patient's will can be held culpable – emergency cases being a possible exception. Thus, the patient's rights are comprehensively protected by criminal law. In practice, however, this legal protection might cause distress with medical staff. First, staff might find themselves in an ethical area of conflict between their medical expertise and a patient's decision against medically indicated treatment and care. The diverging opinions between medical staff and a patient might additionally cause problems and lack of trust in the doctor-patient relationship and thus strain the communication. Also problems within the expert team can result, e.g. if the team members also have different opinions. In addition to the extensive obligation to inform these conflicts can lead to a problem with time management. These tensions might eventually result in criminal legal problems. Legal and ethical decision making might not always be compliant. The question arises how the health-care professionals' dilemma between the obligation to both best-possible medical care and adhere to the patient's will can be resolved, and to what extent also ethical guidelines and legal provisions can offer relief.

Patient's Rights vs. Physician's Rights: The Ethics of Unilateral Do Not Resuscitate Orders

Nneka MOKWUNYE, Director, Center for Ethics, MedStar Washington Hospital Center, Laurel, MD, USA

Patients' rights in the United States of America were codified in the Patient Self Determination Act of 1991. Since then there has been ongoing discussion about the intersection of patients' rights and physician rights. When these two groups appear to be in direct conflict, how does the understanding of those rights aid in mediation? The utilization of the "do not-resuscitate (DNR)" order is one such conflict in medicine. The Center for Ethics at MedStar Washington Hospital Center, a 900+ Level 1 Trauma hospital in a large urban center, has defined "unilateral DNR" to mean "an order to withhold cardiopulmonary resuscitation (CPR) that is written based on the physician's medical judgment without consent from the patient or their surrogate." The institution supports physicians making "good medical decisions" for their patients; this policy echoes those of multiple medical societies in the United States. If an intervention is not considered medically appropriate, it is a physicians' right to refuse to perform the intervention, regardless of any request tendered by the patient. CPR is often a lifesaving intervention; however, there are occasions when CPR exposes health care professionals to potentially dangerous situations without benefit to the patient. These circumstances require careful consideration so as to guard against any paternalistic tendencies disguised as "physician rights;" on occasion there are clear and compelling reasons for an intervention that may run counter to "standard of care." Constant vigilance on the part of an Ethics Committee is necessary to ensure a stable common ground where the rights of both parties can co-exist, especially given the contentious nature of end of life care in the United States. This presentation will discuss the ethics of the physician practice of unilateral DNR orders in the face of patient request for "everything done," and provide a framework for establishing that common ground.

ROOM 3: Patients' wishes at the « frontiers » of medicine

Chair: **Laurence BRUNET,** jurist, Centre d'éthique clinique, Hôpital Cochin, Paris, France

Why I should not have a child at 62 years of age ?

Silviya ALEKSANDROV-YANKULOVSKA, MD, Associate professor of Bioethics, Medical University of Pleven, Pleven, Bulgaria

Background. In 2010 a 62-year-old single Bulgarian woman gave birth to IVF twins. Donor's ova were used for the procedure. Originally the woman was impregnated with 3 embryos, one of which was later removed on the decision of physicians. Being a precedent, the case was widely debated in the media. As a result, changes in the law on assisted reproduction were induced. An age limit of 51 for procedures with donor's ova was adopted. The objective of this report is to present the precedent for Bulgaria case of assisted reproduction and to analyze it applying 4-steps approach for ethical case analysis. Discussion. The case poses at least two moral problems: whether the assisted reproduction clinic was supposed to perform the procedure and whether the society has the right to intervene in personal reproductive choices. Complex information of patient's history, values and medical facts are involved. The patient shared in the media that "Age was not an obstacle for me… I so much wanted to have children". Is the patient's desire alone a good reason for medical intervention? Is age the only "disturbing fact" in this case? Would it be more morally acceptable to perform such procedure with donor's ova in case of young but single woman? Who should decide about the morally acceptable "indications" for assisted reproduction? How far do patient's rights go? The application of classical principalism would give priority to respect for autonomy, especially if the procedure is paid by the patient. However, the interests of the patient, the child(ren) and the society are intertwined. Conclusion. Ethical decisions in the area of human reproduction become more and more complex. Different models of clinical ethics consultation would be of benefit to balance conflicting interests and to reach a well argumented decision.

Considering an Approach to Requests for Post Mortem Sperm Retrieval

Lauren FLICKER, Assistant Director, Einstein Cardozo Master of Science in Bioethics, Montefiore Einstein Center for Bioethics, Bronx, USA

Ethical Question: How can ethics consultants help navigate a request for Post Mortem Sperm Retrieval (PMSR), particularly when the values and wishes of the deceased cannot be ascertained? Approach & Arguments: The international community is divided over how to handle PMSR. France, Germany and Sweden have banned PMSR entirely. Other countries, such as England and Australia, require written consent from the deceased prior to PMSR. The United States, however, has no laws regulating PMSR. In the United States, no clear consensus exists as to how to address these requests from an ethical perspective. PMSR involves such weighty ethical issues as the right to procreate, the right to not procreate, and bodily integrity. Ethical conflicts arise where (1) (as in most requests for PMSR) the did not previously consent to have his sperm harvested for the purpose of post-mortem procreation, (2) the requestor is not legally married to the donor, or, (3) there are concerns that the partner of the donor is being coerced by other family members. Because the typical candidate for PMSR is a relatively young man who has experienced a sudden death, and there is only a short period of time after death to retrieve the sperm, PMSR requests are often fraught with emotion, and both the interests of the donor and the spouse must be protected. Many institutions in the United States require either explicit consent in the form of a written document, or inferred consent from the deceased. Some institutions merely require an indication that the deceased would have wanted to be a father, others require that the deceased have made it explicit that he would have wanted to be a father even in the event of his death. Additionally, some hospitals will only honor PMSR requests from the deceased's legal spouse, whereas others will honor requests from a non-married partner or other family member. Many institutions have no policy governing PMSR request at all, and act on an ad-hoc basis. Opinions are divided over how much weight must be given to what the deceased would have wanted. Some believe that it violates respect for persons to make a father out of a man, even one who has died, without his explicit consent. Others believe that the procreative liberty of the deceased's wife should be given greater weight. Conclusions: In situations where the deceased has not given explicit consent for PMSR in writing, an ethics consult is necessary in order to assist in investigating and balancing the ethical minefield posed by PMSR. This presentation will explore an approach to PMSR requests, using a case example. This approach was developed through involvement in a small number of PMSR ethics consultations; involving meetings with the medical team, the ethics team, and the family, to determine the values of the deceased, the values of the surviving spouse, and to ensure that the widow is not coerced. Such consultations must consider if the deceased and his wife were actively planning on having children, and what the deceased's views on parenthood were. Because the deceased cannot express his values, the ethics consultant must work with his loved ones to determine what his values were. Ethicists at hospitals that do not have a policy concerning PMSR must consider whether it is ethically permissible for persons other than the widow of the deceased to request PMSR and when the deceased's values are not known, whether to err on the side of not allowing procreation.

Requests for treatment by transgender persons in France: Medical coverage and respect for dignity

Lucile GIRARD, Speech Therapist, Phd Life and Health Sciences, Department of Medical Ethics and Legal Medicine, Paris Descartes University, Paris, France

The transgender question is the source of a debate in which medical, social, and legal issues are mingled. Persons suffering from gender identity disorder, or gender dysphoria, must also contend with major difficulties in having their disorder recognized, due to the fact that its symptoms, consisting mainly of a feeling of not belonging to the sex assigned at birth, are so hard to express. This difficulty in expression collides with viewpoints and convictions that are a mixture of taboos, deontology, ethics, and the social vision of the individual. For decades now, medical techniques have made it possible to alter a person's physical appearance to make it conform as closely as possible with the gender to which the person feels he belongs. Nevertheless, the medical procedures available have an impact on the future of the transgender person, and have raised deontological and ethical issues for the health care personnel who practice them. In France, the protocol established by the Sécurité Sociale in 1989 requires candidates to undergo at least two years of psychiatric evaluation before applying for national-health insurance coverage of sex-reassignment surgery. The purpose of this evaluation is to establish the quality of their request, among other questions. Transgender persons believe that in addition to stigmatizing their disorder, the mandatory psychiatric evaluation is an insult to their dignity, in that their word is challenged by questionnaires and interviews carried out by medical personnel who cannot feel what they are experiencing. Currently, many transgender persons refuse to comply with the medical protocol recommended by the highest French health authorities, saying it is too rigid and quite inappropriate to their needs. They have organized their own course of treatment, and sometimes resort to having surgery abroad. Finally, this course of treatment is incomplete if it is not validated by a modification of the person's civil status, or officially recorded gender. As a result, a medical procedure transforming the person happens to be connected to a course of legal proceedings set up to guarantee the individual's rights and privacy. We interviewed 21 transgender people at the beginning of their medical and surgical course of treatment, and one year later. These interviews highlight a reality of clinical practice in which the person is, by the very nature of the procedure, at the center of the treatment. His choices and attitudes are in direct opposition to the scientific conception of medicine. To us, the variety of life experiences we collected demonstrated the overwhelming importance of respect for the person and his unquantifiable, unclassifiable differences. Respect for the expertise the patient has acquired, for his personal truth, decision, and choices, were demands that frequently arose. Moreover, in addition to the medical assistance these persons requested, a need for psychological, moral, and financial support emerged, outlining a profile of these persons as vulnerable individuals who deserve to be treated with sensitivity and care. Our study clearly concludes that transgenderism is a serious challenge to the issue of dignity in both of its dimensions: the dignity of the individual and human dignity itself, insofar as the treatment consists of medicalizing a social ill. Nevertheless, it is important to note that the procedures requested are brutal and nearly irreversible. They raise questions among patients and their friends and families, as well as the practitioners concerned.

Desires and words at play in clinical labial reduction surgery practice

Sara PIAZZA, Clinical Psychologist, teaching assistant, Paris Diderot University, Paris, France

Labial reduction surgery is a cosmetic genital surgery procedure consisting of trimming the labia minora, or small lips, of the vulva. The labia minora are also called nymphae; hence, the other name for this surgery is nymphoplasty. The practice is on the rise in France and other European countries; in the United States, it is a common procedure. Although the general public in France is still unfamiliar with the surgery, it is covered increasingly by the media (television documentaries, magazine articles on cosmetic genital surgery, etc.), and requests for labial reduction surgery are constantly increasing. We instituted a pluridisciplinary research protocol for the medical research study we set up in cooperation with surgeons and dermatologists enabling us to gain access to this particular clinical practice, in the course of clinical interviews with each patient for the procedure. The first part of our talk will review why the practice of labial reduction surgery could be associated with certain ethical issues, linked to excision, on the one hand, and also with regard to national health insurance coverage for a cosmetic procedure. The second part of the talk will be an investigation of what patients are really seeking. They say they want "a prettier vulva, but especially a normal one." What is the wish we should hear behind these words? Whose voice is speaking here? Our talk will especially be based on requests by young women who are minors and have not yet had sexual relations. We believe we understand that this type of request, for surgery on healthy genitalia, as a sign that the patients are troubled by the confrontation with their own genitals; with sexual matters in general; and with womanhood. We see a distinction between spoken and latent discourse, between the voice of the patient and the echo we sometimes detect, of someone else's voice (usually the mother's). How is the clinician abot to hear this voice, which is always divided, and sometimes multiple? In the cooperation with the surgeon, how can we attest to the conflict certain patients face between their desire to undergo surgery and the fears that might accompany the desire? By following the leads such questions open, we offer our own reflection, the outcome of a clinical investigation of the desires and words at play in discourse on labial reduction surgery.

ROOM 4: Advance directives: talking about one's own death?

Modérateur : **Renzo PEGORARO,** MD, President, European Association for Centers of Medical Ethics (EACME), Padua, Italy

Advance Directives: Myths, Limits, and the Experience of Dying

Stuart FINDER, Director, Center for Healthcare Ethics, Cedars-Sinai Medical Center, Los Angeles, USA

With the evolving patients' rights movement and its emphasis on patients' voices and choices, there emerged two powerful "myths" about dying that now dominate in our current Bioethical age. The first is that documentation of preferences via advance directives offers control in the face of death. So prominent is this first myth that it has turned advance directives into almost holy texts that are promulgated as powerful enough to protect us, in our dying process, from the encroachments of modern medical technologies. The second myth, deeply embedded within the first, is that we have control in the face of death. In this paper we explore these two myths via the frame of a series of conversations with a former, elderly colleague. These conversations spanned several years, with the last having occurred two days before his death in late December 2012. Our colleague was a firm believer in advance directives. He'd first written his in the early 1990s and updated it regularly. He'd shared his values and preferences regarding end of life care not only with his family and physician, but with our Bioethics Committee (as part of an educational conference), and even published part of it in an online medical humanities journal. And yet, even in our last conversation, he worried whether he had done enough to ensure that he'd have the kind of end of life experience he wanted – and more importantly, avoid the kind of end of life experience he deeply feared. We utilize his conversations about advance directives to illustrate that as death draws closer, the power of these myths becomes less convincing and the promise of control less certain. We argue that the first myth – of exerting control (especially via advance directives or even through advance care planning conversations) – is the wrong frame for talking about death, and that instead, the focus of such conversations should be the idea of control itself: talking about one's dying and death requires recognizing the limits of one's control, which itself demands practice in talking about the limits of one's control more generally as well as in regards to dying. Thus, in contrast to conversations about controlling death that occur only as part of end-of-life care or in the context of advance care planning as typically understood, we suggest it is more helpful to think about, and talk about, the limits of one's control long before even the most proactive advance care planning advocates would suggest, and perhaps in ways only indirectly related to death. We thus identify and recommend even earlier opportunities (young adulthood, pregnancy and childrearing, childhood itself) for discussion about recognizing the limits of one's control – including as a way to practice talking about the limits of control inherent in dying. We will share excerpts from children's literature as examples of some of the earliest opportunities for recognizing and talking about the limits of our control, even and particularly control over our own experiences or stories, and the endings of those stories – and hence our own endings.

What are patient's preferences with advanced cancer for decision making at the End of Life?

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Identification of individual patient's preferences with advanced cancer is essential for decision making at the End of Life (EOL). Some patients prefer intensive treatments despite high reported toxicities in order to increase chances for prolonging survival. For others, quality of life is the priority. Patient's preferences for either quality of life (QL) or length of life (LL) influence physicians' treatment decisions. Thus, understanding and timely integration of patient's preferences into decision-making process is paramount for patient-oriented care and patient-centered approach for ethics consultation. The aim of this study was to explore patient's preferences for QL or LL and the factors influencing them. In addition, communication preferences about limiting treatment were explored. Methods: We surveyed 194 cancer patients at the outpatient clinic of the National Center for Tumour diseases and the Thorax klinik at Heidelberg University Hospital using a set of written questionnaires. Socio-demographic data, physical health status, preferences regarding QL and LL, communication preferences, cancer-related distress and family role in the decision-making were assessed. Results: The prognosticated survival of 49 % of patients was more than one year, 31% -- ≤ 1 year and 20 % ≤ 6 months; mean age was 63 years (SD=10.3); 68 % were men. 33 % of patients preferred QL while 31 % tended more towards LL, whereas 36 % were undecided. Importance of family members for treatment decisions was associated with striving for LL (p=.01). Patients who preferred LL tended to avoid communications with their physicians about limiting treatment (p=.03). Those patients who strived for QL preferred that their physicians start the discussion of forgoing aggressive treatment as early as possible in cancer treatment (p=.00). We found no impact of age, gender, prognosis of disease, history of cancer and cancer-related distress on preferences for either quality or length of life. Conclusions: This study revealed two important findings for ethics consultation and decisions making for advanced cancer patients: family involvement had considerable impact on patient's preferences and was associated with striving for LL. Patients who strived for LL did not want their physicians to discuss treatment limitation with them. However, studies demonstrate that such communication is a prerequisite for symptom oriented care towards the EOL. Hence, in orchestrating decision making near the EOL it is important for physicians and ethics consultants to involve the family and enable the communication about realistic treatment goals early on.

Dying in the Emergency Room: Patients' voices but Doctors' choices?

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The prevailing attitude amongst most emergency room staff is that the death of any patient is considered a failure. The role of the Emergency room is to save life, to leap in and pull the dying patient back from the brink. In the fast paced and action oriented process of a resuscitation, there is real risk that patients' beliefs, wishes and even advance directives can take second place to the process of 'saving life'. So why is there often a disconnect between what is wanted by patients and what is received? Several studies (Fitzgibbon, 2010:Gill, 2012: Pauls, 2004) have indicated that less than one fifth of patients presenting to Canadian Emergency Room actually have advance directives for care. If they do have them, they are not accessible, or accompanying family members are not aware of these. This is itself a cause for concern in delivering care that accords with the patient's wishes, but what is more of a concern is dealing with the ambiguity that can arise when advance directives do exist, but do not reflect the reflect the reality of the current medical crisis, and must be parsed, interpreted and adapted by medical staff to create a plan of care. In some cases the instructions given by patients to guide their care when they are no longer able to speak for themselves can create confusion and bring about a consequence that they did not intend. As an Emergency Physician, and also an Ethicist, I wished to identify barriers to effective communications about patients' wishes in critical situations. To that end we conducted a survey of the 67 staff physicians working in the Emergency Department of a tertiary/quaternary care teaching hospital, to determine their awareness of and attitude to patients' Advance Directives, and their degree of skill and comfort level with initiating 'end of life' conversations. Specifically, we wished to identify any situations where there would be conflict between a patient's expressed desires, and the type of care that the physician would wish to give, whether that would be resuscitation or palliation, and if there are any circumstances in which they would not follow an Advance Directive. The obvious barriers to these critical conversations are time, and lack of comfort, on the part of both the physician and patient/family member. The emotion and stress brought about by a sudden severe illness can in itself reduce capacity to make decisions. Conflicts arise when we doubt the capacity of the patient, when we are presented with directives that don't make sense in the context of this specific illness, and when we genuinely question that a patient or substitute decision maker understood what they were asking for, especially in the case of a reversible illness. The next step will be to develop a process to identify appropriate patients and families, and to learn the skills required to talk about different paths of care. The goal is to identify potential conflicts as early as possible in the Emergency Department visit, so that conversations can take place to clarify goals of care specific to this particular illness, rather that rely on prewritten instructions that either do not exist, cannot be found, or cannot be applied to all the nuances of potential care.

Patients and healthcare professionals compare notes on advance directives

Sophie TRARIEUX-SIGNOL, Clinical Research engineer, Limoges University Hospital, Limoges, France

Four years ago, due to a lack of public awareness of the 2005 Leonetti Law on patients' rights and the end of life, an outreach program designed to inform the public was initiated at a hospital hematology unit. A jurist in medical law advised the program. It was open to patients (pts), their families, and staff (sgts). The goal of the study was to obtain an objective count of the number of advance directives, and to understand the subjective relationship the staff maintains with the concept. We are reporting the findings of a study that used two complementary methods: a quantitative retrospective analysis of randomly chosen patient files, over a several-month period from August 6 to December 5,2008, and a descriptive qualitative analysis using a verbal questionnaire submitted to healthcare staff on an individual basis. Of the 2,180 new patients admitted during that time, 200 patient files were analyzed (9.2%). The average age of the patients who drafted and signed advance directives was 72.5 years ± 5.6, with a median of 73 years [62;83]. The sex ratio was 1. As time went on, we observed more ADs were written. A total of 12 patients drafted ADs (6%), 6 of which were not on file in the patient records (3%). Patients cited feelings: "I'm afraid of any pain" and wishes concerning their future "I want to be conscious until the end." They all reject "therapeutic obstinacy" (medically futile treatment) without going into detail. Sometimes they specify treatments they would accept or refuse. In rarer cases, a patient indulged in thinking about the meaning of life, reports complex family relationships, or the place where he would like to die. Drafting the directive elicits conversations with family members or the GP. 14 individual qualitative interviews were carried out with pluridisciplinary staff, lasting one hour on average. The term "AD" was discussed: some described it as "too formal," "vague," or "harsh." Some staff members pointed out the lack of a good term, because the problem is death. They attest that the public still knows little about the law. "The patients know nothing about advance directives, which is a problem for the staff member." Objective and subjective deterrents were identified as factors slowing the spread of this knowledge. "ADs scare people." "ADs are associated with death: that's the problem." Death is presented as a taboo subject that inhibits discussions. "Death is never spoken of." Thinking of death, speaking of it, and writing about it rank differently. "Not everyone is capable of doing that." Writing is described as being less innate than speaking, for expressing oneself on themes like the end of life. ADs were sometimes associated with medical liability: "If you ask a patient to write and sign a document, it protects us doctors." Staff members questioned the need to do inform patients about ADs, and how they linked to providing care. Nevertheless, they perceived ADs as a tool that could facilitate discussion, "It's a hint that the matter should be discussed." "It is useful to know that the AD can be offered and re-discused with all patients." To conclude, ADs seem to promote discussion about the patient's personal vision of death with dignity. In the end-of-life context, we are dealing with an ability to express ideas that is part of a collegial approach to caregiving, not the expression of the patient's right to self-determination.

ROOM 5: Understanding the patient : hermeneutics or psychoanalysis?

Chair: **Danièle BRUN,** President of the Medical and Psychoanalysis Society, Emeritus Professor Paris Diderot University, Espace analytique Member, Paris, France

For an ethics of speech in the treatment relationship

Danièle BRUN, President of the Medical and Psychoanalysis Society, Emeritus Professor Paris Diderot University, Espace analytique Member, Paris, France

How can we conceive an ethics of speech in the treatment relationship and state its principles? Is the voice of the patient our guide? Perhaps the voice of the doctor outlines this ethics, in the name of his duty to inform, and the personal concern driving his communications mission. Ethics in the treatment relationship is impossible to conceive in the absence of free speech for each of the partners, and the way each individual inhabits his body, depending on whether it is healthy or ill. Information given to the patient necessarily implies a change for him, in the present and future. It inevitably arouses a conflict within him: a refusal to change grapples with a part of him that is trying to adapt. Clinical narratives and examples show that although announcing a diagnosis or prognosis to a patient is potentially traumatic, this is because the person making the announcement relies on reason and the treatment rationale, remaining ignorant of the unconscious issues his words raise. It is not always easy for the patient to appropriate the effects of the other's word for himself, without expressing them himself, even in a fragmentary way. My suggestion for an ethic of speech in the treatment relationship aims to account for the modalities of expression of this dialectic between the discourse on disease and the patient's words. I also suggest that references to psychoanalysis should be considered pertinent to any theories of the ethics of speech, when the voice of the patient, if not his actual words, is being considered.

Bridging the gap between the patient's first-person voice and the doctor's third- person voice

Colette CHILAND, psychiatrist, Center for Sperm and Egg conservation (CECOS), Cochin Hospital, AP-HP, Paris, France

As the person undergoing the pain, a patient experiences suffering to degrees that he alone knows. Even the most beneficent discourse falls short of the patient's experience. The doctor must simultaneously be in touch with his empathy for the patient and avoid being overwhelmed by emotion. He must not become anxious in the presence of the patient's anxiety. The doctor relies on scientific, objective knowledge he shares with his peers, and on his own personal experience, accumulated over the years. Evidence-based medicine (EBM) tends to minimize these assets. Medical progress is the result of scientific advances, but clinical practice is still an art governed by two golden rules: primum non nocere and good sense. All the doctor can share with the patient is the broad outlines of his knowledge. He must understand what the patient is experiencing, but remain calm, in order to relieve the patient's anxiety and enable him to comply with a treatment regimen that may be very demanding. The doctor's human qualities increase the placebo effect of any treatment. Unfortunately, the wording of the statement of informed consent the patient is asked to sign, and other precautions taken to protect hospitals from lawsuits, tend to foster a distrustful attitude towards the doctor. When the patient signs a form saying he has been informed that general anesthesia has killed a certain number of patients, it does not comfort him. In certain fields of medicine, communicating the diagnosis of a disease and sharing knowledge are especially difficult: psychiatry, for example. It is useless to tell a patient he has delusions. At best, if you succeed in curing him of the delusions, he can understand he used to have delusions, and learn the preliminary signs they are recurring, so that he can go back to the doctor before they get the upper hand. We must protect ourselves from abuse of medical knowledge, or whatever is masquerading as such: for example, when Soviet dissidents were hospitalized as schizophrenics. Certain psychiatrists behaved with exemplary integrity. Robert Stoller (1924-1991, psychiatrist, psychoanalyst, professor at UCLA, the University of California at Los Angeles) did not need any explicit ethical laws and recommendations to respect the psychiatric patient completely. He simply considered everything the patient had said ("the patient's material") as belonging to the patient; he submitted drafts of articles he intended to publish to the patients, and if the patient objected or wished to make changes, he complied with the patient's requests. He came as close as possible to bringing the patient's voice into harmony with the doctor's. Spontaneously, a patient's narrative of his treatment differs from the doctor's. However, a shared narrative can be made to emerge. The patient can recognize himself in the essence of the story.

Hermeneutics for hearing the unheard

Jacques QUINTIN, Philosophy and Clinical Ethics Professor, Sherbrooke University, Sherbrooke, Canada

The world of a person who is ill and suffering is impoverished. The meaning of the individual's life span and future shrinks to a literal and nearly meaningless dimension in which, it seems, life can no longer be taken for granted. The person's entire existence is shattered. Nevertheless, individuals in this situation must make life decisions. Given the impoverishment of this person's world, we may wonder about his competence. Perhaps what the patient's voice expresses under these circumstances is not always to his own advantage. He is often caught in the snares of false consciousness. There are two facets to the issue we face. The point is to determine whether the patient's voice is conveying the truth, and whether caregivers and ethicists are able to sustain this genuine voice or, on the contrary, stifle it. We shall demonstrate that the patient's voice is enlightening, as long as it can transcend from literal to ostensible meaning (Ricoeur). The idea is not merely for the patient to demand his rights, or even express his preferences, wishes, values, and will. The idea is to be able to hear what he is trying to say, in making these demands and in the way the patient expresses himself. The patient's voice is enlightening as long as it opens up the future; that is, another existence. To achieve this, the patient has to "lose the ego and find the I." When we fall ill, it is as though, to some extent, we lose our voice and self. Recovery coincides with the recovery of a voice that expresses various ideas about the future. The point is therefore to give birth to oneself by working on language using language. Speaking turns into an effort to exist. The idea is to speak to "become oneself," not to communicate information. As Heidegger pointed out, understanding is more than simply a means of knowing. It is a way of being: an ability to transport oneself into another life, a life ahead of oneself, a life that makes the manifestation of the self possible. In The Conflict of Interpretations, Ricoeur notes that this understanding of the self emerges "first and always in language" (p. 15). Philosophy understood as hermeneutics is always "a philosophy that begins with language." (p. 28) True, ethics consists in making choices that will have an impact on oneself and others. Nevertheless, according to our interpretation, ethics is no longer limited to obtaining free, prior, informed consent, or to following a set of rules, norms, and principles. Ethics consists of interpreting and pondering what we express when we bring existence to words and words to existence. This thinking process is the primary fact that makes us exist. Ethics implies adopting a critical stance in relation to various ethical discourses. To understand what the patient is trying to say, the healthcare provider and the providee need each other. For this reason, we will be using some of Plato's dialogues (Meno, Lysis) and Aristotle's writing on friendship, in order to show that the patient's voice comes to light as the result of an intersubjective effort that becomes a work of interpretation. The idea is therefore to accomplish a hermeneutics of the patient's friendship, voice, and existence. If medicine has rescued ethics (Toulmin), now it is up to hermeneutics to rescue the patient's voice. We will be guided by the thinking of Ricoeur and Gadamer.

The voice of the patient, the voice of the caregiver: the symbolism of illness, the ethics of (re) assurance

Hayfa NEKAIES, College Teacher, Bioethics Phd student, Faculty of Human and Social Sciences, Bardo, Tunisia

A philosophical reading of the symbolism of the act of "treatment," "treatment" spaces, and "caregivers/patients" attests to the depth of the world of the human. This field of research appears to be quite fertile, hospitable to hermeneutics and therefore to the possibilities of understanding and interpretation. Nevertheless, "what is it to give care while taking care?" How can we behave, at the junction of weakness and technical and cognitive power? How can we guarantee moments of "salvation" for subjects who are hospitalized, and in need of so much support, (re)assurance, and hope? Can we meet the challenge? In other words, how can we ensure that treatment practices improve, and even (re)assure the patients? We know that it is necessary, in particular, to promote a "caregiving" ethic in the hospital. However, how can we identify the issues and procedures it entails? And if every moment in human life, regardless of nature, whether it is a moment of strength or weakness, appears to be unique, how can we cultivate our duties to "treat" or "care"? Many patients are exhausted by the effects of heavy treatment procedures. They are likely to withdraw into their severe pain, to the point where they refuse all contact with the outside world. They are tormented by the situation, by the failure to recover, in particular. If that is the case, how can illness be described? Let us interrogate a concept that is as equivocal for medicine as it is for philosophy. How can we move from the clever mechanisms of the "cure" to the ingenious instances of an ethic of "care"? Meditating on the experience of patients representing some vulnerability enables us to rediscover an infinity of "senses" that often seem to be escaping, otherwise: "senses" that reflect the intensity of a particular "experience," things that were left unsaid, that were ignored or unknown. The values of "courage," "empathy," "solicitude" for the other, and even "attention" or "concern for the other," and of (re)assurance, seem to us to be ineluctable markers for such caregiving practices, because "treatment as a practice corresponds to a specific human activity." This act, which expresses concern for the other, is revealed as a usage for the self that subject to experimentation. It is revealed as a means of behaving in relation to the other that enables us to maintain all of our humanity, to live in harmony with ourselves, as if our self-concern could be diverted to others. Each compassionate activity is unanimously expressed as an active will: the gestures that provide relief for the person who is suffering, while representing a certain patience and worry that are the foundation for "an ethics of care conscious of temporality." The actions of healthcare givers who respect the deontology of their profession, while respecting the many particularities of patients who are staying in hospital spaces, refers to certain ethical guidelines. Their goal is to (re)assure those who are ill and facing moments of weakness. Successful professional caregiving depends on firm moorings to the values of mutuality, altruism, and empathy. Naturally, these values mingle with the social fabric as well as that of healthcare treatment. And through all of this, the spirit of sympathy must not be neglected.

ROOM 6: Children's voice in clinical ethics

Chair: **Franco CARNEVALE,** RN, Clinical Ethicist, McGill University, Canada

Ethics consultation in paediatrics. A matrix to structure the decision-making process

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Introduction Ethical dilemmas in paediatrics pose specific challenges as usually children are not able to fulfill the requirements of informed consent and a triangle decision-making process between physicians, parents and child has to take place. Substitutes for informed consent are the child's assent and dissent as well as the best interest standard. Questions can be asked of how to include the child's perspective in ethics consultation. Methodology A review of reported ethics consultations in paediatric settings is presented, especially focussing on the way in which the child's perspective is being included. Conclusions Demands of enforcing children's rights by including them in decision-making processes and actual practice apparently do not correspond. This is partly due to conceptual inconsistencies of the assent/dissent-concept and the best interest standard; and partly due to established best practices in clinical decision-making which emphasize consensus-building approaches instead of rights-based confrontational approaches. To clarify the different ways of including the child's perspective in the decision-making process a risk-sensible matrix is developed to support decision-making in accordance with the child, the family and the overall clinical situation. This matrix can be used to structure the ethics consultation with or without the child being present.

From an inaudible refusal to "transitory empathetic blindness"

Bénédicte LOMBART, Hd Nurse, Practical philosophy Phd student, APHP / Paris, Paris-Est University, Paris, France

It is clear from the outset that a child's world is incompatible with hospital treatment. A young child incapable of reasoning is worried to find himself in an unknown world, and not naturally inclined to accept treatment. At times, if the child refuses treatment by struggling physically, several adults may hold him down to complete the procedure, setting up a test of strength between the staff and the child. In some cases, the physical restraints applied during the procedure are literally akin to violence. To what degree do situations like this betray a denial of the child's right to express his wishes and have his voice heard? It would seem that this relatively common clinical situation of "forced immobilization" or restraint in pediatric medicine explicitly illustrates the tension arising between the goals pursued by the healthcare staff – providing care for the child's illness, and healing it – and their duty to respect the patient's voice. The frequency with which strong restraints are applied in pediatrics is beginning to be documented thanks to prevalence studies. One of these studies carried out in 2011 at Hôpital A. Trousseau in Paris showed that 14% of the procedures were carried out using strong or very strong restraints. We are now questioning the practice, from a philosophical and ethical viewpoint. Why does the healthcare staff resort to illegitimate use of force? Does the patient's status as a child deprive him of the right to decide? How much freedom is available to a child who is under treatment? The investigation of strong restraint raises many serious questions. We shall explore them within the framework of a thesis in practical philosophy. An exploratory qualitative inquiry ancillary to the philosophical questioning was carried out with thirty-five pediatric care professionals, in order to poll them about a difficulty they face on a daily basis. On the whole, the discourse of all the health care professionals attested to their keen attention to the specificities of the child and profound respect for his needs and rights. Nevertheless, restraint seems to be a specific event that induces professionals to put aside their convictions while they are immobilizing the child. When the healthcare team is using force, their attention is focused on technique, while the child disappears from their field of perception. It is as though the empathy healthcare teams usually display temporarily disappeared while force was applied. In the wake of this observation, we suggest the concept of "transitory empathetic blindness." The consequence of this phenomenon is to silence the child's voice, depriving him of the freedom to express his choices. In practice, professional discussion of these situations makes it possible to shift the paradigm by suggesting alternatives. New possibilities appear: they inolve refraining from responding to the child's movements by restraining him. Instead, the idea is to go along with the child: to respond to his movement with movement, rocking him, perhaps, as Plato suggests. When a mother wants a restless child to sleep, she rocks him in her arms. She does not restrain or immobilize him. She sings, chants, or murmurs a lullaby instead of remaining silent. Let us say that in the full sense of the word, she "enchants" the child, like the frenzied bacchantes, swaying rhythmically in time to her song.

Advance Care Planning in Pediatrics: Experiences and needs reported by bereaved parents

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Background and aims: Severe chronic or progressive diseases call for advance care planning (ACP) to maximize quality of life and ensure patient autonomy. While ACP has been practiced and scientifically validated in adult palliative care, there is little research on ACP for severely ill children and adolescents. However, interest in pediatric ACP (pACP) is increasing. Pediatric ACP differs from the adult setting in several respects, including the psychosocial, ethical and legal peculiarities of the parent-child relationship. The majority of children with severe illnesses have never been able to consent and it is the parents' right and duty to decide in the best interest of their child. Results from a previously conducted systematic review on pACP suggest that pACP is perceived as helpful by parents in ensuring the best care, providing emotional relief as well as facilitating communication and decision-making. However, parents' needs are not always met and negative reactions from emergency services, schools and the community may impede the implementation of advance decisions. Our aim is to investigate parents' experiences with advance care discussions in a community where pACP is not systematically implemented as well as their needs and recommendations regarding future pACP. Methods: We currently conduct semi-structured personal interviews with parents of children/adolescents that have died from a severe illness. Participants are selected by theoretical sampling, aiming at maximum variation of the following criteria: the child's diagnosis, age of death/ability to consent, place of death, involvement of a pediatric palliative home care team and parent gender. The interviews are evaluated using qualitative content analysis and categories are constructed out of the material. Results: The full results of the interview study will be available shortly. On the basis of the first interviews, we hypothesize that advance care discussions are perceived as rather helpful and relieving than distressing by parents and that experienced challenges mainly refer to the current lack of systematic and regional pACP. Our preliminary data also suggest that parents wish early discussions and regular follow-up conferences, appropriate information, involvement of their child in pACP irrespective of its age, a case manager who ensures continuity throughout the pACP process, better cooperation between different care providers as well as education for professionals on pACP. Conclusion: The preliminary data suggest a need for systematic pACP among parents of severely ill children/adolescents. So far, advance care discussions seem to be initiated only at the discretion of the care providers involved. The results of this study may inform the development of future pACP programs.

Maybe there is more to my child than a diagnosis

Suzanne PLANTE, Coordinator, Clinical Ethics Mother-Child Unity, Sainte-Justine University Hospital, Montreal, Canada

The Centre Hospitalier Universitaire Sainte-Justine offers specialized and ultra-specialized healthcare services to the mothers and children of a large city. It serves a public with complex treatment needs in a multi-cultural context. To provide support for clinical staff dealing with unusual situations, a structure has been set up. Its goal is to assist in ethical reflection accompanying decision-making. The clinical ethics unit was founded in 2011. Its mission is to promote the development of an ethical culture and integrate it into the hospital's three functions: as a clinic, a research center, and a university. From the clinical viewpoint, the ethics unit responds to requests for counseling when the healthcare team cannot agree with the parents regarding their child's course of treatment. 53% of these requests are connected to treatment decisions. Of this percentage, half the cases illustrate a conflict of values between the healthcare team and the parents. The following talk will be a review all of these cases in order to detect the source of conflict and improve the quality of the Clinical Ethics Unit's interventions. In the past several decades, rapid scientific progress, combined with clinicians' determination to practice evidence-based medicine (basing their decisions regarding disease diagnosis and treatment on mathematical estimates of a benefit/harm relationship), have altered the treatment relationship. We looked at the factors that contributed to engendering conflicts between clinicians and families. We observed that clinicians tend to privilege decisions based on the specificity of the diagnosis they have reached, instead of integrating the specificity of the child and his family context. This scientific culture, based on the type of pathology, gives priority to the physiopathological side, which is technically possible. However, in doing so, it is liable to ignore a vision of what the patient or his family might perceive as being "good." Moreover, communication is hindered by the clinicians' use of scientific language: "rates of survival, risks, and complications." Many parents are shocked when they are spoken to in this way. In their eyes, the doctor has failed to understand the meaning of this particular disease for their family and their child. In this context, clinical ethics is aimed at re-establishing communication and recentering the questions on the many contextual matters. Clinicians tend to limit themselves to asking what can be done technically. However, the clinical ethics counselors must often go beyond technical solutions and remind the healthcare team to think together with the families, about the meaning of the diagnosis and the treatment that can be provided for it. In this presentation, we will describe how the counseling our clinical ethics unit provides makes it possible to point out which values are in conflict and re-establish dialogue, by assuring each individual he will be heard. The ultimate goal is to recenter the purpose of treatment on the child as a unique individual, while respecting all the parties involved. The experience of the ethics unit at CHU Sainte Justine demonstrates the importance of a clinical ethics counseling service for complex situations the healthcare team often experiences as impasses or nonsense in terms of treatment. The role of a clinical ethics unit is to provide a narrative dimension to collective decision-making by integrating families, and the meaning they attribute to their child's disorder or disease.

ROOM 7: Questions of Ethics, a documentary from Anne GEORGET

Chairs: **Gérard LEVY,** MD, PhD, Aix en Provence, France and **Séverine MATHIEU,** Sociologist, Université de Lille 1, France

An unusual immersion in the heart of the Center for Clinical Ethics at Paris's Cochin Hospital. The Center counsels physicians, patients, or patients' families dealing with ethically complex medical issues. Where are the boundaries between "beneficence" and "non-maleficence"? How can a situation be clarified, so that dialogue and trust prevail? How can a balance be achieved between divergent points of view, between the patient's autonomy and his or her family's grief? Filmmaker Anne Georget concentrates on the Center's private discussions and interviews surrounding five cases, analyzing them in all of their complexity.

15h30-15h45 COFFEE BREAK

15h45-17h45 PARALLEL SESSION (2)

ROOM 1: Narrative ethics

Chair: **Céline LEFEVE,** Philosopher, Georges Canguilhem Center, SPHERE, Paris Diderot University, Paris, France

Teaching ethics and empathy through movies for approaching patient's needs

Pablo G. BLASCO, Scientific Director SOBRAMFA Medical Education & Humanism, São Paulo, Brazil

Because people's emotions play a specific role in learning attitudes and behavior, educators cannot afford to ignore students' affective domain. Although technical knowledge and skills can be acquired through training with little reflective process, it is impossible to refine attitudes, acquire virtues, and incorporate values without reflection. Learning through aesthetics -in which cinema is included- stimulates a reflective attitude in the learner. Because emotions and images are ubiquitous in popular culture, should be the front door in students' learning process about feelings. In fact, when systematically incorporated into the educational process, and allowed to flow freely in the educational setting, emotions make learning both more memorable and more pleasurable for students. Empathy, from the Greek empathy, means understanding someone else's feelings. Can empathy be taught? Is it possible to establish a learning process for empathy? Those who are involved in medical education know that a broad range of biographical experiences and situational factors influence the development and promotion of empathy. Some authors emphasize the importance of art, literature, cinema and reflecting over one's own life in developing empathy. Literature has plenty of examples, and choosing appropriately is always a dilemma. Cinema, as well, is capable of portraying a tremendous spectrum of what empathy is about. As the audiovisual resources are permeating our current culture, opportunities for teaching with cinema are well suited to the learners' environment. This learning scenario stimulates learner reflection. In life, important attitudes, values, and actions are taught using role modeling, a process that impacts the learner's emotions. Cinema is the audiovisual version of storytelling. Life stories and narratives enhance emotions, and therefore set up the foundation for conveying concepts. Movies provide a narrative model framed in emotions and images that are also grounded in the everyday universe. To foster reflection is the main goal in this cinematic teaching set. The purpose is not to show the audience how to incorporate a particular attitude, but rather to promote their reflection and to provide a forum for discussion. Reflection is the necessary bridge to move from emotions to behavior. The experiences we have with cinematic teaching span more than a decade. Our experience affirms the effectiveness of using the movie-clip methodology in which multiple movie clips are shown in rapid sequence, along with facilitator comments while the clips were going on. Emotions are a universal language that help people to bridge cultural differences and achieve agreed upon interpretations and mutual understanding. At this point, we can envision why those "intangibles" issues, difficult to teach and to assess, in which empathy, compassion and commitment are included, could be endorsed through the cinema education methodology. Some authors' publications on this area 1.Blasco PG et al. Using movie clips to foster learners´ reflection: Improving Education in the Affective Domain. Fam Med 2006; 38(2) 94-6 2. Blasco PG et al. Teaching Through Movies in a Multicultural Scenario: Overcoming Cultural Barriers through emotions and reflection.

Patients coping with a rare genetic disease speak out

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The patient is destabilized by the occurrence of a rare and little-known disease. Terms like "being lost" and "sheer hell" are the only metaphors strong enough to express the disorientation and great vulnerability to which the person is exposed. These words are often used to describe the experience of living without knowing, a period of wondering and wandering, when the patient is assailed by questions and incredulity. Sometimes his doctors even "accuse" him of having a mental illness, making him feel guilty. We felt it was important to develop these three terms ("rare," "being lost," "hell") as images that convey the exclusion of the subject who is in great distress, at a loss for stability in the very structure of his identity. Other terms – "accident," "mistake," and "mutation," often associated with "suppression," – are attempts to express why the genetic anomaly, and its pejorative connotation, is affecting him. At that point, the genetic dimension prevails, as a key to understanding why he has been struck down by disease. The patient is greatly tempted to identify with the diagnosis that has been established, with the genetic anomaly that has been named, sometimes reduced to its genotype shorthand. The patient is liable to feel reduced as well: to a diagnosis, reduced to a disease, devoid of any other existence as a subject. Perhaps he is more fragile, and altered, but he does contain the potential to develop as a person. This talk is based on research into the narratives collected from 16 patients or parents.

How medical narratives (narrative ethics) can be used to improve health care services in rural remote communities of sub-saharan africa

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Background: Majority of patients accessing health care services in rural remote communities of Sub Saharan Africa have low literacy level, do not believe in modern medicine and there is large educational gap between the health care professionals and the patients which in many ways have influenced poor health care outcomes in areas where there are already established health care facilities. Aims: This paper explores how medical narrative (narrative ethics) can be used in poor rural settings to improve the health care services. Approach: Systematic review was done on the effect of narrative medicine in the USA and other parts of Africa. The work of Tod Chambers and Rita Charon was highly used to come up with the recommendations. Results: Findings shows that, introducing narrative medicine in the settings will improve health care services by bridging the existing doctor-patient gap, help acceptance of modern medicine practices, improve doctor patient communication, better diagnosis and treatment. Recommendations: Health care professionals in the rural-remote settings in SSA should be trained on how to integrate narrative ethics in the daily clinical practices to build a good communication relationship with patients to influence their health seeking behaviors.

Stories Matter: Narrative and Clinical Ethics

Martha MONTELLO, Philosopher, Associate Professor, Department of History and Philosophy of Medicine, University of Kansas School of Medicine, Kansas, USA

What methods are effective to give patients' voices the central place they deserve? Current emphases on patient empowerment and autonomy often fail to give voice to patients' expressions of values, fears, and hope. When cases are ethically complex, understanding patients' perspectives and life experiences is essential to forming the successful therapeutic relationships necessary for resolving troubling moral problems. One particular challenge raised by the patients' rights movement is the difficulty of working effectively with family members when the patient is in the process of becoming incompetent. How can we make sure the patient's voice is still heard and honored when he or she can no longer have a direct voice? Although the basic principles of medical ethics serve well as guides, reminding us of certain common core values, such as respect for persons, beneficence, and considerations of justice, they are insufficient in cases like this. A narrative approach fleshes out and reshapes principles so we can see moral dimensions as embedded in the flow of people's lives and values. This paper describes a contentious case of a 55-year-old man who was diagnosed two years ago with Parkinson's disease. Now, he is slipping into incompetence. His voice is in danger of being muted and ignored. Although he has repeatedly voiced his wish that his wife care for him in their home, she fails to give him his medications, resulting in repeated hospital admissions. His physician has asked the ethics team to agree to a legal effort to remove the patient's wife as his guardian and to turn the task over to a willing daughter. The wife is angry and distrustful. The patient is sad and agitated when away from his wife. This paper describes two elements of narrative competence I used as the ethics consultant to help this family. Together, they provided an effective method for keeping the patient's voice at the center as moral decisions about his care were being made. One element of narrative competence is interpretation. One must listen for the moral dimensions of the wife's story: what has mattered to her over time, and how that is being threatened by her husband's illness. One must ask a reader's questions about character, voice, and plot, the "moving parts" of stories. Using stories in this way, we can understand people's needs and choices – how their values fit together in their lived lives. We need to perceive a "mattering map", a projection of what is most important to the person telling the story. Another element of narrative competence is "narrative thinking," an ability to draw on certain stories, in our own past lived experience or through the stories of others, to make new patterns for moral action. Over two hours, I used these elements as the patient's wife told me her story. Gradually I heard what her husband's illness meant to her. As the strong one in their long marriage, he had made all the decisions on their farm. She worried that the safety and consistency of her life depended on his remaining healthy enough for this story to continue. Together we imagined new patterns that held assurances that she would not be alone. She finally spoke the word "Parkinson's" and asked to learn how to take care of her husband. A narrative approach to ethics problems can help patients express their voices. And it can help families to feel less isolated, absolve them of guilt, and reveal the best possible choices under terrible circumstances.

"Tell Me About Your Mother:" The Power of a Simple Question to Reveal a Patient's Voice through a Family Discussion

Constance PERRY, Philosopher, Associate Professor, Drexel University, Philadelphia, USA

As part of my clinical ethics fellowship at Loyola University Medical Center, outside of Chicago, I was fortunate enough to shadow the late, great David C. Thomasma on a few ethics consults. The experience taught me much about how to elicit and empower the voice of the patient, while remaining compassionate to all affected by the often emotionally-laden situation at hand. My focus in this talk is on one of David's tools. It is a deceptively simple question, "Tell me about your (insert proper relational term here)." Those who are expected the speak for the patient are asked to share their perceptions of the patient. This process helps to elicit the voice of patients who cannot speak for themselves, especially in the absence of prior discussions of care wishes or advance directives. The patient's voice is elicited in at least six ways. The question: 1. Empowers loved ones of the patient as the authorities on the patient qua person. 2. Promotes context-rich considerations of the current state of affairs in relation to previous decisions and statements made by the patient, even if the patient did not overtly discuss medical treatment wishes. 3. Focuses on describing the patient qua person instead of vice versa. 4. Helps loved ones focus on something other than their own grief, fear, pain and concerns. 5. Reconnects family members through the sharing of common experiences, thus developing a cohesive voice at a time that can stress familial bonds. 6. Finally, it promotes a greater understanding of the reasoning behind surrogate decisions (and possibly for any "tensions" with the family). This tool is only one among many. But it is a deceptively powerful tool for clarifying the voice of patients who lack decisional capacity. It extends beyond substituted judgment by strengthening familial bonds, easing the stress of being a surrogate and reminding health care professionals of the person within the body being treated. The resulting narrative demonstrates the real, lived interconnections between the patient, her loved ones, community, and others, which illustrate the patient's value, priorities, etc. The patient's voice is revealed via the stories of those closest to her. Cases will help to demonstrate the power and limits of the question and the practical skills that ethicists need in order to use this tool effectively. This includes considerations prior to scheduling the family meeting, procedures during the meeting and considerations for after the meeting ends. This tool is a different focus than mediation or consensus building. It gives priority to the discovery and expression of the patient's voice. This approach will thus not be definitive for all cases. But it is the rare case in clinical ethics where the patient's voice is not relevant.

ROOM 2: The role of patients in health care education

Chair: **Thomas SANNIE,** President, Association of Hemophiliac Patients, Paris, France

Collective medical deliberation and decision-making: an ethical experiment for medical students

Ralph BALEZ, social psychology associate Professor, Faculty of medicine, Bretagne-Occidentale University, Brest, France

Third- and sixth-year medical students from the Faculté de Brest take part in a simulation of collegial deliberation and decision-making. The students must give and justify an opinion on amputating the gangrenous right foot of a fictitious patient (a 77-year-old man, who is insulin dependent, paraplegic with severe cognitive disorders). The clinical picture leads most of the professional doctors we questioned (6 of 7 experts) to recommend amputation and argue in its favor. The primary decisive criterion is the gangrene. Under such conditions, the patient could be expected to survive only 15 days, while undergoing extreme pain due to the gradual "rotting" of his foot. The odor would also repel his family. Nevertheless, in this fictitious case, the patient and his family are clearly opposed to amputation: "I was born with my foot, and I want to die with it." It is interesting to see how individual students elaborate and appropriate the collegial medical decision: how they justify it, present it to the family, and defend it when confronted by dissenting opinions from colleagues. To what degree will these students take the voice of the patient and his family into consideration? Soon they will find themselves making and justifying these types of decisions in real-life situations, if they are not already residents. The experiment is carried out in parallel in the third and sixty years of medical school (two times 80 students, divided into groups of 12 to 15). In certain groups, specially prepared "secret agents" will argue for or against amputation. We can therefore make a comparison between groups of students who have had a few weeks of training in recognizing patient symptoms (in year 3) with those who are already well seasoned hospital doctors used to making medical decisions (in year 6). We also observe groups that reach a consensus opinion fairly easily as well as groups where a single dissenter refuses to give in and argues his case. How will future practitioners reach such decisions? Will they set up a structure in which each doctor can communicate with the family? To what degree will the wishes of the patient (and his family) be considered? Might considerations other than the patient's survival emerge (his comfort, his wishes)? How much weight will a consensus carry, and what criteria will be cited to justify it to the patient's family? Would it be useful to endow such expert committees with an official dissenter, in charge of systematically arguing against the majority, for the purposes of improving decision-making procedures and accounting for the patient's voice? Or will such a role emerge spntaneously? The discussion following the exercise is taught by doctors and psychologists. They review the opinions expressed publicly (in the form of a vote) and privately (on paper) as the discussion proceeds. Findings enabling us to answer these questions are currently being analyzed and will be developed at the conference.

Integrating patients in professional healthcare training courses: What are the issues?

Emmanuelle JOUET, Researcher, Education Sciences, Research Laboratory, EPS Maison Blanche, Paris, France

In the past several years, in many countries, clinical skills education programs have been developed for doctors and other healthcare professionals in training. As a corollary of this trend, patients are also increasingly involved in what has become a treatment partnership with the professional. Likewise, an educational partnership is developing, defined in particular by the active presence of patients in copiloting and implementing initial and continuing education programs for healthcare professionals. Each of these approaches raises a number of different challenges. The fact that they are being implemented concomitantly demands an investigation of the conditions and issues of a curriculum oriented towards the prospect of the patient as a partner with healthcare professionals. We raise the following questions: how much weight should be given to knowledge derived from patient experience and/or "profane" knowledge, as opposed to academic and clinical knowledge? What skills can these new types of knowledge impart? What dialogical and organizational prerequisites does this type of cooperation entail? What curricular and educational devices are most favorable to making these approaches operational? These programs trigger the interaction of heterogeneous identities and social representations: how will such interaction be addressed? To explore these issues, we suggest a review of the conditions and principles for action set up by the Bureau Facultaire de l'Expertise Patient at the Université de Médecine de Montréal. It can be a model for achieving real integration of the patient-partnership dimension in academic curricula.

The voice of the patient, the ear of the caregiver, the attention of the lawmaker

Sandrine BRETONNIERE, Sociologist, CADIS, EHESS/CNRS, Paris, France

A sociological commentary on the personalized itineraries of contemporary French cancer treatment. The patient's voice was constituted as a legal right by the law passed in 2002. The legislative activity established the civil rights of the person who is disabled or happens to fall ill, so that he feels less doomed, less discriminated against, and less given up on. People testified that they were hurt by society's gaze. In fact, they told of being excluded from ordinary congress with their peers, even in conjugality and sexuality, or with friends they thought were close. It pinpointed the additional burden of subjective or moral offenses that are woven into the awareness of vulnerability as soon as the diagnosis is announced. The 1998 Healthcare Estates General did not herald any break in the historical and cultural bond established between the social and the medical, or between the patient and his doctor. They spawned the rallying cry of the weakest and most isolated, discovering or recalling the scope of the efforts necessary to live as part of a community while receiving treatment. Patient collectives did not challenge the medical establishment described by Michel Foucault, or renegotiate the identity or role of the patient in the interactionist sense of the sociology of French healthcare. However, the testimony that was heard conveyed the experience of the subject with a disease, aware of the difficulties he encountered to adapt to the reform of the personalization of treatment, associated with new trends in therapy and the chronicization of severe pathologies. Our talk underscores the activity of patient participation in treatment, which also solicits their significant other. It questions the future of patients' rights, based on an ethnographic investigation of the new healthcare players, identified and described in local and territorial healthcare networks. It shows that they are a source of strength for the patient, a motivation for his existence. Likewise, the personal resources that make treatment successful are reconstituted in the world outside medicine: the social and economic realms, but also the psychological, emotional, relational, cultural, or political ones. Symbolic and spiritual aspects are as important as physical or corporeal ones. This talk expresses the conviction that patients' rights are an accomplishment of the ideals of democratic public health if they help to better articulate the realities of social life with the demanding necessities of today's treatments. However, they betray the interests of the patient when they fail, or when certain individuals refuse or renounce their rights.

"They Don't Believe Me": The Voice of Patients Living with the Pain of Sickle Cell Disease (SCD)

Cynda RUSHTON, Professor of Clinical Ethics, Johns Hopkins University, Baltimore, Maryland, USA

Clinical ethics consultants are increasingly called upon to address concerns about adequate treatment of pain. A particularly challenging population are patients with chronic pain, such as those living with sickle cell disease (SCD). Sickle cell disease is a common inherited disease, affecting one in every 400 African-American babies and 200,000 infants born in Africa. Acute episodes of severe pain are the hallmark of SCD and the most common reason for hospitalization beyond infancy. Embedded in these cases are a number of common myths that may reflect clinician assumptions and biases about patients with SCD. Myths such as (1) patient reports of their pain are unreliable, (2) requesting particular medications and doses indicates drug addiction, and (3) the levels of narcotics necessary to adequately manage SCD pain will lead to opioid addiction. These myths can contribute to labeling and mischaracterizing these patients as "drug-seekers", and may indicate negative clinician attitudes about the treatment of pain associated with patients with the diagnosis of SCD, their race and socioeconomic characteristics. In part due to patients' need for narcotics during painful crisis, and providers' reluctance to provide them, patients with SCD have described adversarial relationships, lacking in respect and empathy, with health professionals. Because the majority of patients with SCD are of African descent, and clinician communication and pain management have been shown to be worse with patients of color as compared to whites, the adversarial relationship between SCD patients and providers may be magnified. As a result, their treatment may be compromised and exacerbate existing inequities. Morally-salient attitudes held by health professionals, such as respect and empathy (or lack thereof), are known to influence the quality of health care received by patients. Clinical ethics consultants have a critical role to play in uncovering clinician attitudes, and in redressing the often unacknowledged and invisible aspects of caring for patients with SCD. This experiential and interactive presentation is designed to explore the experiences of people living with SCD related to pain and suffering; identify barriers to adequate pain assessment/treatment; highlight how issues of race, class, and ethnicity can shape perceptions and assumptions about patients in regard to their experience and treatment of pain; and suggest strategies for overcoming the negative attitudes and biases of clinicians faced with the pain and suffering of people living with SCD. As a means of integrating the voices of patients, we will show professionally made 10-minute documentary video (with French subtitles), entitled "They Don't Believe Me" that is part of a larger curriculum that includes 5 other films, The films were developed through interviews with patients with SCD, their families and interdisciplinary clinicians who care for them. This presentation will highlight how film can be a useful medium for capturing patient narratives and can be integrated into professional training programs - including the training of clinical ethics consultants - to illuminate the issues and trigger more meaningful dialogue.

ROOM 3: The patient's role in Cess

Chair: **Sylvie EPELBOIN,** MD, Bichat hospital, AP-HP, Paris, France

The Patient's Voice: The thread that completes the tapestry

Thalia ARAWI, Founding Director, Salim El-Hoss Bioethics and Professionalism Program, Clinical Bioethicist, Vice Chair, Medical Center Ethics Committee, American University of Beirut, Faculty of Medicine and Medical Center, Beirut, Lebanon

While the patient's rights movement has played an important role since the late 1970s in the West, this voice has hardly been heard in other areas of the world marked by medical paternalism. This presentation will highlight the experience of the American University of Beirut Medical Center, the first hospital in the Arab World that started offering bedside ethics consultations. During my presentation, a number of issues will be highlighted: 1. What bedside ethics consultations taught us about the importance of listening to what patients (and their families) have to say about their values, desires and wishes in tandem with listening to members of the healthcare team, 2. When healthcare teams (regardless of their dedication) work in isolation, the process of resolution of an ethical issue does not really materialize. It is only when both voices are heard that the tunes fit together to create the needed harmony that will lead to better choices, better decisions and greater patient satisfaction, 3. What ethics consultants can learn from patients and healthcare teams, 4. When patients and healthcare team feel that they are encouraged to speak up and are being "listened to" and that their voices play an important role in the resolution of the issue, more patients and more physicians see the importance of ethics consults and ask for them. Reflecting on his paintings Monet once said that it is the parts that give insight into the whole. The same can be said about our experience of ethics consultations.

Symphony for Zoé

Claire FAUCHER, Ethicist, Health and Social Services Centre, Laval, Canada

We would like to present Zoé's story in order to illustrate, share, and discuss a path taken by the "patient's voice," as well as the potential role of the "clinical ethicist" (CE) in bringing out this voice, taking it into consideration, and determining its various levels of meaning. The voice does not exist in isolation. It is associated with bonds and a greater social context the CE must account for. The story unfolds in several phases. We will describe them, and then analyze the ground covered by the patient's voice and the CE's contribution. Phase One: Bringing out the patient's voice. In February, the case was submitted for ethics consultation. Opinion diverged between a clinical team and a patient, Zoé, on the need to change a medical ventilator. The team wished to prevent a risk of imminent death of which Zoé appeared to be unaware. The ethics consultation made it possible to bring out Zoé's voice. She requested palliative care and withdrawal of treatment. Phase Two: Once Zoé's voice had been heard, how could her wishes be fulfilled? Many individuals were involved. How could their voices be harmonized? In this case, the CE assisted with and coordinated setting up palliative care at home, and a protocol for the withdrawal of treatment. Phase Three: How far should such a voice carry, and by what means? The staff members questioned Zoé's use of social media and the fact that she had contacted celebrities. Likewise, a filmmaker was making a documentary about her. Would these actions have an impact on the option chosen, and on confidentiality? Next, a few days before the date planned for withdrawal of treatment, a daily newspaper printed an article on Zoé. At the same time, Bill 52 on medical aid in dying was submitted to Parliament. This made the clinical team very uncomfortable. They wondered how much support they would receive from their colleagues and the hospital. Moreover, the hospital was worried about the possible media impact of the situation. The CE was again solicited. Phase Four: Is the patient's voice unequivocal? Zoé changed her mind on "D-Day," expressing a desire to postpone the procedure for a few months. Did the fact that she had a voice in her treatment change the way she saw the future? Conclusion: At various stages, the CE can play a major role in bringing out the patient's voice, making it heard, making it active, and interpreting its meaning. The CE can also open a space where all the voices involved can be heard, and facilitate communication.

Advocacy, education, empowerment? Constructing the role of the patient in clinical ethics consultation.

Louise CAMPBELL, Lecturer in medical ethics, School of Medicine, National University of Ireland, Galway, Ireland

In the literature on clinical ethics, scant attention has been paid to date to the role of the patient in the consultation process. Although hearing the patient's voice is a prerequisite for providing patient-centred care, there is little or no evidence that clinical ethics consultation is itself 'patient-focused'. In order to develop an ability to listen to the patient's voice, providers of clinical ethics services need to understand how the patient's role has been constructed in and by the process of clinical ethics consultation. Existent contributions to this discussion in the literature question the need for education and advocacy for patients. Rasmussen (2012) regards patient advocacy as a challenge to the appropriate role of the clinical ethics consultant, while Fiester (2012) considers that all parties in the consultation process have a right to advocacy and therefore that privileging the interests of patients above those of other stakeholders is inadmissible. Antommaria (2012) argues that advocating for a particular set of interests runs the risk of denying the legitimate moral uncertainty which forms the basis for ethics consultation. Those who argue for the education of patients usually do so on the basis of a concern with the question of access to, and representation in, the process of clinical ethics consultation (Neitzke, 2009). The real focus of these discussions, however, is the nature of clinical ethics consultation and the role of the ethics consultant, not the needs and perspectives of the patient. Further, the discussion homogenises patients as a group, by assuming that in all cases the patient requires advocacy, or needs someone to represent his or her interests. If the patient's voice is to be heard and heeded, what is needed is a differentiated understanding of the role of the patient in the ethics consultation process. Whereas many patients do require support or advocacy, others are experts in relation to their own illnesses, and may well be able to provide education to clinicians and clinical ethics consultants about their situation and perspective. The aim of this presentation is to further explore the construction of the patient's role in the process of clinical ethics consultation and to examine whether the field of clinical ethics consultation may be advanced by paying attention to the strengths and capacities, as well as the vulnerabilities, of patients.

Making a Case for Patient Involvement in Clinical Ethics Consultation

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Should patients be involved in clinical ethics consultation (CEC) and – if yes – what is the appropriate form of participation? The practice whether and how patients are involved in CEC is very varied. This is attributed primarily to the institutional and political setting of the service (Fournier et al., 2009). The ASBH recommends an open access policy concerning CEC – explicitly including patients – as "an important way of ensuring that the rights and values of all stakeholders are respected". However, patient involvement (PI) may also have undesirable effects such as burdening or irritating patients. Studies about benefits and burdens of PI in CEC are largely lacking. Several aspects of PI should be distinguished: 1) Access to general information about the CEC service, 2) ability to make a request, 3) notification about a planned CEC, 4) possibility to give informed consent to a CEC taking place, 5) participation in a proceeding CEC, 6) involvement in the follow-up, 7) access to documentation, and 8) possibility for evaluation. The following case study is presented and evaluated: A 21 year-old patient with a severe congenital facial dysplasia had undergone 25 facial surgeries during childhood and adolescence. Now, the patient was faced with a decision to be made on a further elective operation with a functional and aesthetic objective – for the first time as an adult person. At that point, the surgeons couldn't recommend this intervention without reservation due to their own concerns about potentially negative corollary for the patient's career: authenticity and acceptance in his preferred profession as a social pedagogue for handicapped people could be compromised by a "normalized" appearance. Therefore, the surgeons called for a CEC with the patient. Results The patient was informed by the physicians about the possibility of a CEC. They both agreed to ask for a CEC. At the beginning the ethicist stated that the primary goal of this meeting was to support the autonomy and decision making of the patient. After this intervention, the patient was able to express his thoughts more clearly and independent of the preferences of his mother, who seemed to have been implicitly dominant in the past discussions. It was revealed that he needed more time to make up his mind; consistently, the result was to postpone the operation until the patient would be confident to decide. A summary of the results was provided. At the end of the session, the patient expressed relieve and gratitude for the consultation. Discussion The presented case shows some possible benefits of PI: Participation of patients can be crucial to identify the right focus on the ethical problem in the first place. Furthermore, an atmosphere of trust may allow the patient to reflect and express his concerns freely for the first time. Especially in settings like this one, the patient's first personal perspective plays a crucial role – just because he is one who has to live through this. This raises a responsibility to listen to the patient's voice carefully. A summary can be an important instrument to confirm the patient's authority. Points to consider: 1) Patients have a right not to get involved in a CEC. 2) Weakened patients may not benefit from PI, even when they are supported. 3) Strengthening patient autonomy should not lead to overemphasizing individual interest. 4) PI increases the requirements for confidentiality

ROOM 4: Special needs and the rights of psychiatric patients

Chair: **Nicolas FOUREUR,** MD, Centre d'éthique clinique, Cochin hospital, AP-HP, Paris, France

Good treatment and psychiatry: how can we change the order of the discourse?

Aude CARIA, Director, Mental Health, Psycom, Paris, France

Users of the psychiatric system are not ordinary users. They bear the stigmata of "madness" that make them outcasts from the community of ordinary human beings. This distinction is a blow to the foundation of ethical conduct: the ability to recognize another person as an alter ego of oneself. This blindness is endemic not only in society as a whole, not particularly aware of mental illness: it can also affect healthcare professionals. It emerged as an issue in discussions held within the framework of ethics seminars at Paris's Sainte-Anne psychiatric hospital. The goal of these seminars is to reflect upon how respect for the patient is implemented in treatment practices. The workshops focus on a dilemma in caregiving: "How can the ethical intention of protecting a person weakened by illness be reconciled with respect for the user exercising his rights and freedoms?" It is an ethical tension shared by all healthcare professionals, but potentialized in forced psychiatric treatment and practices depriving the patient of freedom. Its analysis leads us to think that a psychiatric good-treatment policy must be based on the possibility for healthcare teams to respect the rights of users of psychiatric services, without sacrificing the benevolent intentions that are the ethical substrate in which any caregiving practice is rooted. The person who is living with a mental health disorder must be recognized as a subject in his own right and an alter ego of the caregiver. Such a recognition requires a paradigm shift, in which the voice and experiential knowledge of the user of mental-health services is no longer excluded. Instead, it must be placed at the center of discourses on mental health. Healthcare professionals will foster the emergence of psychiatric good treatment by making it easier for users to speak out, by listening to what they say about illness and treatment, and by respecting it as a valid discourse.

The effects on mental-health patients of sharing stories about illness, treatment, and recovery

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The "Users' Voice" group is a program that was set up to enable certain outpatients from Psychiatric Institute of the Federal University of Rio de Janeiro (UFRJ) to tell students at the institute about their experiences with illness, treatment, and recovery. It was implemented in 2005, following a modification of the course in Psychopathology I. The users take an active position, speaking freely with the students. All semester long, the group meets regularly with the students in psychology, as well as with students from other universités in Rio de Janeiro, and community mental-health service staff and users who express an interest in the program, from Rio de Janeiro and nearby towns. This talk is an effort to determine the possible effects of the program on the outpatients who participate in the group, sharing their experiences. We interviewed ten of the participants using a semi-structured template. The interviews were transcribed and the content was analyzed according to a phenomenological-hermeneutical method. The transcriptions were analyzed by two researchers working independently. They classified the process of producing and sharing their personal narratives into various categories, broadly divided into the benefits (sociability, responsibility, training professionals sensitive to patient experiences, learning, recovery, relationship with the group, having a voice, helping others, being involved) and the difficulties (putting one's experience into words, exposing oneself, sometimes not feeling well enough to participate, stigma). The difficulties pointed out by the study show us the users' need for reliable support.

The human rights of the citizen-psychiatric patient: Reality or sustained fiction?

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The topic of human rights for psychiatric-citizen-patients in relation to forced treatment has been one of the central issues in the legal-ethical debate of recent years. The issue not only highlights the voice of the patient in their struggle for the genuine acknowledgement and, above all, respect of human rights, it also challenges the role and the authority of psychiatry. For more than a century (cf. the Alleged Lunatics' Friend Society, 1845), activist patients and survivors of psychiatry have been denouncing practices judged to be barbaric, inhumane, and contrary to any notion of care; practices that nevertheless persist, as the UN Special Rapporteur on Torture Méndez clearly stated in his report of March 2013. Has official condemnation of such practices led to greater respect for or attentiveness to the patient's voice? Reality shows a different picture, that those human rights remain mostly fictitious, theoretical. It seems that patients typically have the right to be silent and to submit themselves to the precepts of the omnipotent and corporatist medical model which firmly endorses the necessity of care as the moral and legal justification for forced treatment. The patient's voice struggles to overcome not only authoritarian and repressive legislation, but also collusion between legal and psychiatric institutions, certain patient or family organizations, and trade unions. Too often, these influential lobbies continue to tolerate indefensible practices, thus reneging on their legal, moral, and ethical obligations. The patient's voice is subject to manipulation in a power play engaged in by all of these different interest groups, sometimes sustained by a nearly unshakable faith in the concept of parens patriae. Many countries have passed even more repressive mental health legislation, resulting in significant increases in forced hospital admissions and in forced treatment. This development is in total contradiction with international human rights legislation, particularly the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD, 2006/2008), despite the fact that the document is legally binding. Lest we forget, this Convention was drafted in order to compensate for the persistent weaknesses in the European Convention for the Protection of Human Rights (1950) and the Principles for the Protection of Persons with Mental Illnesses (1991). The paternalistic aspect of some of the articles, specifically in relation to freedom and self-determination, shows that the legal, moral, and ethical status of the psychiatric patient continues to be considered differently from that of other members of society. This talk will focus on the tensions related to the status of the voice of the psychiatric-citizen-patient in its struggle for human rights. It will use examples of action and proceedings to demonstrate how, in the spirit of claiming both rights and obligations, the voice of psychiatric patients and survivors condemns the focus of debates on psychiatric treatment around points of procedure or on politico-corporatist issues, rather than on the principle of fundamental human rights which would allow the advent of a radically different paradigm in terms of psycho-social distress and care.

The voice of psychiatric patients: problems and progress, as experienced by a group of Belgian mental health mediators

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Images of a confined world where madness confronts scientific objectivity still cling to the specialty of psychiatry. The most vulnerable of vulnerable patients, often cut off from family and community, many psychiatric patients reside in locked wards, subject to enforced hospitalization. Under such conditions, what chance do they have to make their voices heard? In August 2002, Belgium passed a patients' rights law that obligates psychiatric hospitals to organize mediation teams in charge of examining complaints about violations of patients' rights. The great majority of these mediation team members are specialists who are careful to combine an independent position with patient accessibility. Now that the law has been in effect for a little over a decade, they can evaluate their experience. Although progress has undeniably been made, there is still a long way to go before the voice of patients with mental illness is considered as valid as that of patients who have other illnesses. Respect for patient autonomy is the value presiding over the inspiration for the 2002 law. There is no doubt that this value is gradually wending its way into a medical culture that was hitherto saturated with paternalism. Psychiatric medicine now deals with concerns that were ignored a few decades ago, such as providing hospitalization conditions that are not degrading to human dignity, engaging in dialogue, and making efforts to work with the patient, and restore his autonomy as a subject. Likewise, more attention is paid to the patient's existential environment. These matters are now considered fundamental to providing mental health care. Patient self-help groups are thriving, and users' committees are being founded inside hospitals. Nevertheless, problems remain. The concept of rights for the mentally ill raises an immense objection: are they capable of exercising such rights? Mental disorders inevitably lead to the question of competence. How can individuals whose mental functioning is altered by disease make valid choices that promote their own interest? To what degree are they capable of processing information, choosing a doctor, consenting to treatment? These questions attest to the reluctance of public officials and medical authorities to permit the mentally ill to exercise their rights as patients. As for the specific application of each right, the data gathered by the mediation teams indicates that the right to receive quality care and the right to consent are the ones that are cited most frequently in the complaints that were filed. However, note that the most important finding pointed out by the mental health mediation teams was the immense hope these patients had for a better-quality relationship with the medical staff. On this point, psychiatric medicine is not fundamentally different from other healthcare specialties. In the case of mental illness, the patients make it strikingly clear that relief for their psychological suffering requires not only medication, but also greater human closeness.

The role of mental illness in the development of a plan of care

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It is often assumed that patients with a psychiatric diagnosis that could interfere with their decision making ability, lack the capability to make rational, informed medical decisions. The involvement of patients in the development of their plan of care can be an effective method to increase the likelihood that the patient will comply with the plan of care. Involving patients with a psychiatric diagnosis in the development of their plan of care is vital to ensuring that the voices of these types of patients are heard. A similar assumption is made about patient representatives who also have a psychiatric diagnosis that has the potential to interfere with the representative's ability to make rational, informed medical decisions for a patient. Acting upon this erroneous assumption about patients or their representatives has the potential to bring about some of the following unintended consequences: causing a breakdown of communication between the care team and the patient or their representative, preventing a patient from having their autonomous medical decisions taken into consideration during the development and execution of their plan of care and lastly, causing patients to undergo unwanted and possibly ineffective treatment. The existence of this issue is not likely to change anytime soon because according to the World Health Organization, 27% of adults in the European Union has experienced a mental disorder and according to the National Institute of Mental Health, an estimated 26% of American adults suffer from a diagnosable mental disorder. Given the prevalence of mental illness, it is likely that ethics consultants will continue to deal with the issue of mental illness during ethics consultations. My hope for this paper is to promote dialogue and encourage reflection on the misconception that patient's or patient representatives with psychiatric diagnoses lack the ability to make rational, informed medical decisions. In an attempt to foster reflection on this aspect of ensuring that the patient voice is heard, this paper will do the following: 1. Discuss the factors that should be considered when determining whether or not a patient or a patient representative with a psychiatric diagnosis should be involved in the development of a plan of care. 2. Discuss the ethical considerations for when these circumstances arise. 3. Illustrate through examples from actual consultation cases, the complexity of decision making about whether a patient or a representative with a psychiatric diagnosis should be involved in the development of a medical plan of care. 4. Provide the practical considerations for ethics consultation services that aim to ensure that the patient voice is heard regardless the patient's or their representative's psychiatric diagnosis.

Advance directives in mental health care as tools for helping patients' voices to emerge and as institutional challenge for psychiatry

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Advance directives and other forms of surrogate decision making are widely regarded as institutional tools helping patients' wishes and choices to be heart in medical situations of mental incapacity. Although these instruments have been developed primarily in somatic medicine e.g. intensive care, oncology and palliative medicine they are currently increasingly discussed in the field of mental health. This oral presentation gives an overview on the state of the art of advance directives and other forms of surrogate decision making including psychiatric joint crisis plans. The author, a psychiatrist and medical ethicist, will further discuss ethical challenges of advance directives in patients with mental disorders: Besides concrete information on the preferred medical treatment in concrete clinical situations the mental capacity of the patient at the time of delivering the directives is essential. Challenges within the different concepts of competence and different empirical data regarding the clinical judgement of mental capacity in psychiatry are presented. The „Decisional Competence Assessment Tool for Psychiatric Advance Directives" and empirical studies from the US on advance directives in patients with mental disorders and the judgement of the treating psychiatrists on these patients directives are discussed. Ethical conclusions are drawn for handling advance directives in psychiatric practice with a special focus on the perspective of patients' rights and institutional tools helping patients' voice to emerge.

ROOM 5: Medically assisted death: international perspectives

Modérateur : **Véronique FOURNIER,** MD, Centre d'éthique clinique, Cochin hospital, AP-HP, Paris, France

A radical example of respect for patient autonomy: enacting the Belgian law on euthanasia

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Belgian law defines euthanasia as a procedure carried out by a third party (who must be a physician) that intentionally ends the life of a patient at the patient's request. Therefore, two prequisites must be met prior to any euthanasia process. First, the patient's request must be made explicitly, willingly, and repeatedly, in the absence of external pressure. Second, the patient must meet with a doctor. After examining his personal convictions, this doctor may agree to carry out the procedure at a time to be designated by the patient. In fact, the patient's expression of volition is not limited to requesting euthanasia. It continues to be operative until the procedure is over, because the patient alone is responsible for choosing the date and time for the euthanasia. The doctor promises to be present when the time comes. He therefore accepts the patient's decision. Hence, we may say that the position occupied by each protagonist is the opposite of the one they occupy in the usual doctor-patient relationship. In a case where a procedure eventually results in an act of euthanasia, it is the patient who decides and the doctor who consents! Apparently, many doctors and nurses experience being confronted with a patient's request for euthanasia as a dispossession of their prerogatives as caregivers. True patient autonomy would free the patient of the necessity to request something from a doctor. Indeed, there is a price to pay when one claims and assumes autonomy, rejecting all authorities aside from oneself, and that price is loneliness. The patient who wishes to end his life can go ahead and do it himself. This is the argument that has incited many American states and Switzerland to prefer what is commonly called assisted suicide to euthanasia. In assisted suicide, a lethal dose of barbiturates is provided for the patient, and the doctor is not involved at the last moment when the patient himself decides to take the drugs. Yet in reality, there is very little significant difference between administering a euthanizing drub orally or intravenously. It is the patient who drinks what the doctor brings to him; it is also the patient who can start the IV flow of drugs, previously placed there by the doctor, at the time of his choosing. The Belgian legislation that authorized acts of euthanasia under certain conditions does not stipulate how the lethal substance will be administered. Actually, it is still up to the patient to choose. The main difference between euthanasia legislation in the US and Belgium is that in Belgium, the doctor is obligated to watch over the process from beginning to end, so that all goes smoothly. This possibility is actually a way of not abandoning the patient to his sad fate, and staying beside him until it is over. The "final appointment" is then an opportunity to share time with the patient's family. In the days leading up to it, the last moment should be prepared for by the clinical staff, although everyone must be free to be involved or not, according to his or her own wishes and those of the patient. In this way, patient autonomy does not rule out a demonstration of solidarity.

Physician-assisted suicide and the conflict between patients' choices and health care workers' own values. A medical ethical analysis.

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Around the world there are patients who, in the face of an incurable disease, raise their voices and make an autonomous decision to end their lives at a time of their own choosing. In some countries, patients have the option to receive medical assistance in suicide under specific conditions. Elsewhere, legal restrictions make physician-assisted suicide (PAS) impossible, which leads to the fact that quite a few patients travel to countries such as Switzerland in order to receive aid in ending their lives. For example, between 2001 and 2004 more than 60 percent of the people who killed themselves with the help of the Swiss right-to-die organization "Dignitas" came from Germany. Physicians who are confronted with the autonomous request for assistance in suicide quite often find themselves in a moral conflict. On the one hand, it is conceivable that physicians principally aim to respect the patient's self-determination, but against the background of their own values are not willing to provide aid in dying. On the other hand, there might be physicians who could imagine supporting a terminally ill patient in suicide, but are put at risk for sanctions due to restrictions imposed by professional associations. For example, in 2011, the 114th German Medical Assembly adopted a new model professional code in order to explicitly prohibit PAS, although more than half of the German population and one in three German physicians are in favor of PAS under specific conditions. The aim of this contribution is to analyze PAS from an ethical point of view. In the first part, we discuss conceptual aspects of the patient's self-determination and the care of the physician. In the second part, special focus will be laid on the possible conflict between the patient's autonomous choices, the physician's personal values and the normative statements of the various professional associations, which at worst impedes clinical decision-making. In the end, it will be argued that PAS can be seen as ethically justified under specific conditions. From this follows that medical associations and professional societies should stronger than hitherto acknowledge the differentiated attitudes towards PAS among the general public and the physicians and that they should strengthen the individual doctor-patient relationship instead of ex ante preventing physicians from assisting patients in their suicide.

The practice of euthanasia in the Netherlands

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The practice of euthanasia in the Netherlands is significant as it expresses the voice of patients and their choices. This practice also made clear that in a process after a request to be helped to die the relationship between doctor and patient changes in a fundamental way. Research uncovered the need of patients and physicians for a deeper and more reciprocal relationship in order to be able to overcome psychological barriers to end the life of another person as opposed to the usual professional distance between physicians and dying patients. It also points to a philosophical-ethical issue of a conflict of duties between the duty to protect life and the duty to alleviate suffering. In order to assess the legal conditions of acceptable euthanasia physicians and patients develop a reciprocal relationship in order to assess the nature of unbearable suffering and the moment of ending a life. From a philosophical point of view this relationship is to be qualified as 'medical friendship', within the limits of a professional relation.

Patient vs. doctor: the cases of euthanasia and non-treatment decisions (NTDs)

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Euthanasia – that is, drug-induced, medicalized killing by a doctor of a patient upon his voluntary and competent request – is legal according to statute in the Netherlands, Belgium and Luxembourg. The Netherlands has practiced euthanasia since 1973; however, it was only formally legalized in 2002 when a new law entered into force. From that year onwards, not only do doctors have an exclusive right to perform euthanasia; patients have a corresponding right to ask for it. Still doctors are under no legal obligation to do so; they may opt out, and refer a patient to another doctor who might be willing to comply with the patient's request. There is thus a right to ask for euthanasia but no right to get it. Yet in practice it happens that doctors experience pressure coming from both patients and their next of kin; after 2002, apparently some patients behave as if they do indeed have a right that euthanasia be performed. Besides being a practical-clinical conflict, this is to a large extent an ethical conflict as well: Doctors may be reluctant to kill the patient for moral reasons, the main argument being that it goes against everything they have been thought in medical school – i.e., that their role is to preserve life, not to take it. Seriously ill patients, on the other hand, may perceive life as of no value anymore, thus believing they are "better off dead" by means of euthanasia. Also in cases of non-treatment decisions (NTDs) – that is, withholding or withdrawing life-sustaining treatment – there is potential for conflicts. It is at the discretion of a doctor to determine whether there is indication for treatment. For example, he might see, or judge, treatment in a particular case as futile. But the patient might disagree violently and may, in contradistinction to in euthanasia, value life so highly that he thinks he is clearly "better off alive" no matter how small chances are that e.g. resuscitation following cardiac arrest would be successful. Accordingly, some (like patients with advanced metastatic cancer) do want futile treatment – even though there is no right to such. "Futility" is a notoriously difficult concept both clinically an ethically, notwithstanding the fact that occasionally there are clear-cut, paradigmatic instances of what it would mean. These kinds of conflicts are regularly framed in terms of patient autonomy. The present paper is equally focussed on doctor autonomy, an issue that has been given much less attention than it deserves.

Request for aid in dying and assisted suicide: A Swiss debate with universal parallels

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The request for aid in dying may be the most radical and disturbing expression of the patient's voice. It expresses a timeless demand for ultimate autonomy. For centuries, people have contemplated voluntary death, "the door that is always open" (Epictetus). In countries where active aid in dying (euthanasia and/or assisted suicide) is permitted by law, the question is especially acute. In Switzerland, euthanasia is prohibited, but assisting another person in ending his or her own life is permitted by law. In fact, assisted-suicide organizations have been so active that assisted suicide is overtly practiced, in an organized way, in part. Moreover – and Swiss legislation is unique in this respect – the medicalization of assisted suicide is not mandated by law, although medical personnel are usually involved. Informal directives restrict access to assistance in dying to patients with terminal diseases or conditions. Moreover, recent jurisprudence (by the European Court of Human Rights, in Gross vs Switzerland) challenges the idea that it is legal for medical assistance in suicide to be granted or refused according to the doctor's conscience alone. This decision opens the debate on liberty rights and claim rights in this field. Lastly, because the case of Gross involved a request for assisted suicide motivated by the generic infirmities of great age, rather than by a terminal disease as such, this type of request is at the center of debate. Studies on the request for assistance in dying usually concern end-of-life situations, and examine the reasons for the patients' wish to die. These studies have demonstrated the importance of existential and narrative aspects such as the disintegration and loss of identity, as well as the loss of control of one's own biography in its final phase. The findings have led to a deeper understanding of the situation faced by patients expressing a wish to die, and an evolution in treatment practices. However, the development of a nosographic discourse on the wish to die reinforces a trend towards medicalization, and makes the question of the genuine wish to die even more opaque, in some cases implicitly excluding it from the field of the thinkable. Where aid in dying is legal, this is an unsatisfactory situation. It necessitates clear conceptual, ethical, and practical responses to the following questions: How can the status of the request for aid in dying be defined, and what obligations, if any, does it engender for society as a whole? For medical practitioners, in particular? What legal safeguards protect those who make the request, and those who grant the request, or not? In justifying the request for aid in dying, how much weight should be given to the diagnosis of a terminal disease, or of a disease causing severe pain or disability? Assuming that a request for aid in dying in the absence of severe disease is considered to be acceptable, to what degree will that change the doctor's position and the type of medical expertise required? The Swiss case functions as a "moral microscope" increasing the visibility and urgency of these questions. The answers to them are relevant well beyond Switzerland's borders, and concern the general debate on assistance in dying in many countries where the question is on the agenda.

Requiem medically assisted suicide: allowing a variety of voices to be heard

Delphine ROIGT, Jurist and bioethicist, Consultant in clinical ethics, President of Clinical ethics committee, CHUM, Montréal, Canada

In the past several months, Quebec has initiated reflection about treatment for terminally-ill patients, include medically assisted death. A special commission took the first steps towards reflection on the issue, with the goal of studying the right to die with dignity. It drafted a report submitted to the authorities on March 22, 2012. After that, a committee of expert jurists was mandated to stipulate the legal parameters to be considered in order to implement the recommendations of the special commission, in particular the one legalizing euthanasia, officially termed "medical aid in dying." Currently, a bill is being reviewed by parliamentary committees (Bill 52 on end-of-life care). This bill includes "… specific requirements for certain types of end-of-life care, namely terminal palliative sedation and medical aid in dying. It prescribes the criteria that must be met for a person to obtain medical aid in dying and the requirements to be complied with before a physician may administer it." (excerpt from Bill 52). A group of clinical ethicists belonging to the Association Québécoise en Ethique Clinique (AQEC) submitted a report to the Parliamentary Commission on Bill 52, in which they wonder about actual application of the law in the current context of treatment in Quebec. It is important to be aware that euthanasia is prohibited under Canadian criminal law, which defines it as "a deliberate act undertaken by one person with the intention of ending the life of another person to relieve that person's suffering." Thus, throughout the Canadian provinces, euthanasia is a criminal offense. The report also pointed out several difficulties, obstacles, and incoherencies, particularly in the process surrounding a request for euthanasia, its implementation, and its aftermath. Moreover, the group raised questions about the overall spirit of Bill 52, in that it erects patient autonomy as an absolute dogma, to the exclusion of other important ethical considerations. The goal of this talk is to present, on the one hand, the ethical issues raised by Bill 52 and, on the other, the principal recommendations suggested by this AQEC group. The most important recommendation concerns proceeding with an ethical deliberation when a request for medical aid in dying is made, in order to take all the dimensions of the person into account, as well as a clarification of the issues and values. This process will make it possible to facilitate the implementation of the decision and its endorsement by all those concerned, because it will make sense, and not only because it is what the patient wants or what the law requires. The request for death must not be the option that is chosen "for lack of anything better," but the best option under the circumstances. Reflection must proceed from modification of the norm. It is important to remember that legalizing medical aid in dying does not relieve the ethical malaise of the individuals who request it, that of their family members who watch it, or that of the professionals who must respond by accepting or rejecting it.

ROOM 6: The role for autonomy in clinical ethics: an endless debate

Chair: **Robert Baker,** Ph.D., Union Graduate College -Icahn School of Medicine at Mount Sinai Bioethics Program, New-York, USA

Treatment refusal in schizophrenic patients: autonomy or irrationality?

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People with schizophrenia are often characterized by medical doctors as globally irrational and unable to make informed decisions. This characterization has serious implications in schizophrenic patients in term of their right to refuse treatment and exercise rational autonomy. Consequently, the principles of beneficence and nonmaleficence are largely invoked when the decisions made are high-risk and possibly fatal. To highlight the ethical issues of refusing potential life-saving treatment, we present three cases of schizophrenic patients suffering from AIDS, terminal renal insufficiency and cancer who refused their treatment despite relative stability of their mental illness. The local Clinical Ethics Consultation was called to discuss these cases. The first patient was a 49 years old man suffering from AIDS and refusing the antiretroviral treatment. The question of the psychiatric team was: how to force the patient to take his treatment? The second patient was a 28 old man refusing dialysis. The question of the medical team was: was it ethical to let this patient die from renal insufficiency if dialysis was impossible? The third patient was a 40 old man who developed a testicular cancer and refused surgery. The question of the team was: how to perform surgery against the will of the patient? After discussion, the three schizophrenic patients were considered to be able to make decisions in relation to their values and life expectations despite their mental illness and symptoms still present such as delusions. In the first two cases, readjustment of the treatments was possible after negotiation. In the last case, refusal of surgery still persisted and was accepted by the medical team. This case study tried to show that autonomy in schizophrenic patients remains a strong ethical principle, and that decisional capacity to refuse treatments is a context-specific construct in such patients frequently labelled as irrational by virtue of the status of their mental disorder.

In favor of minimalist clinical ethics

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If health is defined as the ability of the subject to live according to his own norms (Canguilhem, 1966), and not merely as his ability to adapt to society, and if the role of the doctor and treatment is to enable to the patient to become and remain the author of his singular life, perhaps the appropriate posture of the healthcare specialist in relation to the patient's voice involves adopting a minimalist ethic (Ogien, 2007). How is a minimalist ethic applied in clinical practice? Neutrality is the first ethical principle. More precisely, the specialist must remain morally indifferent in relation to himself; he should not judge another individual's concept of a good life, the relationship he maintains with his own body, his values, wishes, etc. This comes down to demanding that the healthcare provider respect the patient's autonomy: his capacity to formulate opinions, make choices, and take action "as a function of his values and beliefs" (Beauchamp, Childress, 2008). Non-maleficence is the second principle. "Do no harm" essentially signifies not wronging the patient. Equal consideration of all is the third principle. Were we to state this idea in terms of principlism, we would call it the principle of justice. We are arguing that it is possible to combine these ethical postures into a single, unified principle that would suffice to inform our practices. Could we not ponder clinical ethics using a single, unified principle for the purposes of avoiding any paternalistic, normative tendencies, in particular, in the treatment relationship? In light of the deliberations in clinical ethics carried out at the Nantes CHU, related to the beginning and end of life, we advocate such a minimalist clinical ethic, based on a single, unified principle: that of non-maleficence. Not harming the patient means more than merely "not taking action." Its primary requirement is respectful attention to the patient's voice and body language, the first signs of his identity and values. As a result, doing no harm leads to positive actions: help and solidarity, not only between individuals, but also between the State and its citizens (Mill, 1990). According to such an ethic, "doing no harm" covers two types of behavior. The patient's autonomy must be respected and protected, and the clinician may also act on the patient's behalf, when he asks us to, or would ask us to, if he could. In a secular, pluralistic democracy, a minimalist approach to clinical ethics is imperative.

Not a Lone Voice: Healthcare Decision Making as a Relational Process

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The primacy of individual autonomy in western bioethics promotes the idea that patients should be the ones to make voluntary decisions regarding their healthcare. Legal provisions for treatment consent generally require patients themselves to authorize clinicians to provide care. Individual patients are the decision-making units, whose explicit and voluntary consent is required for interference. In the current age of person-centred care, there is renewed emphasis on encouraging active patient engagement at every level of care design and implementation. It is only when patients are incapable of making decisions that families or other appointed individuals can decide on their behalf. This presentation reports findings from a larger study on the intersecting factors affecting diverse patients' and families' ability to make complex healthcare decisions. It explores patient perspectives on individual decision-making and the role of family in such processes. Findings derive from interviews with a range of patients (n=47) in a cosmopolitan Canadian city. Participants came from diverse cultural/ethnic backgrounds (Caucasian, Jewish, Aboriginal, Indo-Canadian, and Chinese). Interviews averaged 45 minutes and were recorded and transcribed. Transcripts were analyzed within and across respondents using qualitative thematic coding techniques. Grounded theory methodology informed an inductive thematic analysis to explore instances when patients discussed family influence and involvement in their healthcare decision-making. Data analysis was conducted by two research team members and facilitated by NVivo 9 software. It involved a constant comparison across and between data to explore patterns and variations of decision-making experiences. In describing their healthcare decision-making processes, participants with families reported incorporating relational considerations or involving loved ones in collaborative decisions rather than deciding independently. Five intersecting themes were salient. First, participants considered the potential impact of their conditions and treatment decisions on family members or their own familial role and obligations. Second, participants were motivated by their family's hopes, fears, and desires in their treatment decisions. Third, while many participants were capable of making decisions on their own, independent decision-making left some feeling alone. Fourth, participants trusted that their family members knew them best and would make appropriate decisions for them, even if they had not specifically discussed their healthcare preferences. Fifth, many participants considered family involvement as an integral emotional support system and assurance of appropriate decision-making during difficult times. While family considerations and involvement influenced some participants' decision-making processes or led them to abandon their original treatment preferences, participants were not concerned about familial infringement on their freedom to make decisions. These findings shed light on how clinicians can truly respect patients' relational autonomy. Participants did not always want to actively engage in care decisions or consider their own voices as the only relevant ones in healthcare decision-making. Person-centered care thus requires clinicians to attend to patients' relational context and engage the patients and their support networks accordingly.

English Physicians' Perspectives on Patient Preferences and Advance Directives

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Patient-autonomy is an essential element of modern medical practice. Changing demographics and the increasing number of patients with dementia raise question about how patients' wishes should be taken into account when they are no longer able to express themselves. One instrument to this is the advance directive, whose legal recognition was advocated by the Council of Europe at the beginning of 2012. Yet, although most Western countries emphasising patient autonomy, such as England have adopted legislation on advance directives, they are only rarely implemented in practice. In spite of these legal requirements, decisions regarding treatment withdrawal at the end of life remain an urgent problem for physicians. This paper presents the results of a qualitative study combining direct observations and semi-directive interviews conducted over a period of 4 months in clinical settings in England. It explores English physicians' perspectives and attitudes towards end-of-life decisions when patients lack capacity to make decisions for themselves. The paper aims to examine how English physicians take into account the patient's voice and to explore the (potential) role of advance directives. The study focuses on (1) problems that emerge when deciding to withdraw/-hold life-sustaining treatment from both conscious and unconscious patients; (2) decision-making procedures and the participation of proxies/relatives; and (3) experience with advance directives and difficulties with regard to their implementation. The analysis reveals the concern of English physicians to respect (only) authentic patient wishes. This concern reflects the public debate and English legislation. The analysis further shows how the physicians accommodate (or not) their concern to respect patient preferences with the difficulty to determine an incompetent patient's will and how this influences their attitudes towards advance directives. The understanding of problems to implement advance directives within a particular national context is much needed to inform the ethical analysis and the development of relevant policies.

Alone and Anonymous - A Case Against Ogien's Minimal Ethics

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The French philosopher Ruwen Ogien has an interesting moral theory. In his book "L'éthique aujourd'hui" (Gallimard, 2007), he advocates for a minimalist ethical approach, according to which, what each of us do to ourselves concerns only to each of us, as long as whatever we do does not interfere with others' lives: "Son idée centrale c'est que ce nous faisons de nous-mêmes n'a pas d'importance morale, tant que nous ne causons pas de tort direct à autrui." (p.196). Consequently, Ogien proposes three basic normative principles: "1- Indifférence morale du rapport à soi même; 2- Non-nuisance à autrui; 3- Égale considération de chacun." Although Ogien's proposal is appealing, it has some difficulties which the author acknowledges, but to which he does not credit enough strength. The persistent moral paternalism (as he called the human tendency to interfere in situations that supposedly do not concern any other than the autonomous agent responsible for that situation - suicide, for example), according to Ogien, has its roots in two kinds of arguments - the human dignity and the human nature. It is this second one that I wish to address here. "O solitário anônimo" ("Alone and Anonymous") is the title of a 20-minute documentary by the Brazilian anthropologist Debora Diniz featuring the real story of an old gentlemen who tried to kill himself by starvation. The movie starts right after he enters the hospital, conscious, but very weak. The health professionals have a hard time trying to perform nasogastric intubation. He tells them many times not to do what they were doing, complaining about the violence of such an act. The health professionals answer gently that: "As long as you are here we have to do that." As time passes and he gets better, it becomes very clear that he is not a typical user of the Brazilian Public Health System. Graduated in both Law and Philosophy, lover of classical music and chess, he slowly agrees to explain his reasons. He was not happy with his life. But he did not have enough courage to commit suicide. So he decides to leave his city (Brasília) and go to a small town where he knew he "would not have any attachments to anyone". The plan did not work because he decided to leave the apartment he rented to die, afraid of giving too much trouble for the owner after his death. So he went to a public place. But the attachments he was running way from, caught him anyway. People could not simply watch him lying on the sidewalk, and called an ambulance. Although this example (of how difficult it is to disregard the invisible attachments each human being has with each other) is of just one single case, I believe that it is remarkable enough to present the strength of the argument of human nature against the possibility of a minimalist ethics. Also, to demonstrate how difficult it is to hear the patient's voice when it contradicts our instincts, and sense of duty.

The Voice of Living Donors for Liver Transplantation: Autonomy and Agency

Rosamond RHODES, PhD philosopher, Director of Bioethics Education, Icahn School of Medicine, Mount Sinai, New York, USA

As the living donor advocate for the liver transplant program at my institution, my task involved interviewing each potential living donor to determine whether or not the decision to donate was informed and voluntary. In philosophic terms, I was assessing whether the donors' decisions are autonomous and genuine expressions of their agency. By the time potential donors reached me, they typically spent weeks, months, or years contemplating their donation, speaking with doctors and family members, reading the literature, and surfing the internet to explore the experiences of others. If any, these choices bore the marks of careful deliberation and considered judgment: These decisions were not rash, impulsive, or whimsical. Surprisingly, potential donors described their decisions to undertake the significant risks and harms involved in donating up to 70% of their liver in different ways. The terms they employed echoed familiar theories of autonomy, namely: identity, authenticity, self-creation, future oriented consent, higher order desires, self-legislating, etc. Donors' accounts of how they reached their decisions, and the variety of concepts that they employed in describing their thoughts and their motivations, suggested that many of the standard views of autonomy and agency are similarly flawed. For the most part, philosophers present their positions on autonomy and agency as vying theories or models of how to correctly conceptualize the decisions for which people can be held responsible. For example, they define autonomous actions as only those that conform with higher-order volition, or those that are reflectively endorsed, or those that are self-authorized, or express an absence of alienation. Some potential liver donors spoke in aspirational terms, saying things like, "I want to be the kind of person who helps people." Others expressed identity with their agency, saying things like, "I am a Christian, like a good Samaritan I help my fellow man." Others explained that "I couldn't live with myself if I didn't try to save him." And others said things to the affect that, "Of course I'm afraid and would prefer not to, but this is the right thing for me to do." Some, typically those who seem most committed to the donation and least ambivalent, even say things like "I have to." "I couldn't do anything else." "I have no choice." To the extent that individuals explaining their organ donation decisions have reliable insight into their own mental processes, the range of ways in which they characterize their decisions challenge the simplistic philosophical conceptions of autonomy. In my presentation, I shall review a number of classical and contemporary models of autonomy and agency. I shall use examples of living liver donor statements to demonstrate how they exemplify some particular position, but would not easily fit with others. Appealing to the variety of ways that agents described their decisions, I shall argue against the standard, simple, essentialist, or perfectionist views of autonomy and, instead, urge a pluralist view that encompasses all of the above and aligns with Aristotle's and Hobbes's broadly inclusive and less specific notions of autonomy and agency.

17h45-18h00 COFFEE BREAK

18h00-19h00 KEY-NOTE CONFERENCE:

The voice of inaudible patients: Someone's else words

Hilde LINDEMANN, Philosopher, Michigan, USA

Chair: **Anne FAGOT-LARGEAULT,** Philosopher and psychiatric, Professor Honorary, Collège de France, Paris, France

For the next few days we reflect on the patient's voice, and why it is sometimes faint or goes altogether unheard. The patient may be too ill to speak, or too incapacitated for her voice to express her autonomous wishes. She may speak a foreign language. She may be deaf and lacking an interpreter qualified to sign medical terminology. Her own views may be outshouted by a patient association that presumes to speak for her. Or she may be the target of prejudice (she's fat, she's poor, she's old) that makes it easy for socially privileged people to discount or ignore what she says. In this talk I examine a rather different, more subtle kind of voicelessness—one that is pervasive, causes moral trouble in the clinic, and goes almost altogether unrecognized. It is the voicelessness that is brought about by having to use someone else's words. To explain, I begin with Ludwig Wittgenstein's remark in the Philosophical Investigations: "To imagine a language means to imagine a life-form" (§19). In this section, Wittgenstein develops the idea that speaking and understanding language is a part of, and specific to, a particular way of life. The words in the language mean what they do because of how they are used by those who inhabit that way of life; the inhabitants shape the language to serve their own purposes. I contend that the language specific to the life-form of the clinic does not always serve the patient's purposes. It looks deceptively like the patient's language, which is why the problem goes unnoticed, but it is actually what Wittgenstein would call a suburb of that language (§18), and it's an unfamiliar one at that. Using the analogy of Caliban in The Tempest, I describe the patient's plight when the language of the clinic does not serve her needs, offer some case examples that make the problem more visible, and suggest a partial solution.

19h00-21h00 COCKTAIL RECEPTION, RÉFECTOIRE DES CORDELIERS

SCHWAGER AWARD FOR CLINICAL ETHICS

Friday, April 25, 2014 morning

9h00-10h30 PLENARY SESSION:

Patients' values, healthcare professionals' values: which ethical conflicts?

Chair: **Mike PARKER,** Philosopher, Oxford University, United Kingdom

Recognizing nurses in clinical ethics consultations

Franco CARNEVALE, RN, PhD, Clinical Ethicist, McGill University, Canada

In North America, there is a growing recognition of the importance of promoting the inclusion of nurses in clinical ethics consultations. Two principal reasons underlie this phenomenon. First, nursing has established itself as a legally and ethically autonomous profession. Although physicians are responsible for prescribing a medical plan of care, nurses are responsible for adapting prescribed treatments within their nursing care. Nurses are expected to provide care in line with ethical and clinical standards of care in nursing. Nurses are considered responsible for their care; they should therefore be involved in treatment planning. Second, nursing has developed research, theory, and practices that have contributed to important shifts in ethical outlooks in North American health care. For example, nursing has actively countered paternalism by promoting clinical models for patient-centered and family-centered care as well as models for an ethic of care and relational autonomy to counter "legalistic" autonomy ethical orientations. Moreover, research evidence has highlighted that nursing actions have a major impact in ensuring patient safety. Nursing ethicists have advocated for the recognition of nurses as moral agents; as important agents engaged in the promotion of ethically-attuned and equitable clinical care. Moral agency also sheds light on moral distress experienced by nurses, as they are commonly confronted by moral binds between professional responsibility for nursing care with limited authority over medical and administrative decisions that significantly impact upon their nursing care. Clinical ethics consultations should therefore actively promote the inclusion of nurses' perspectives.

Conflicting values, conflicting powers

Daniel DEFERT, Sociologist, Past President of AIDES (first French association against AIDS), Paris, France

Collectively and internationally, the first AIDS patients faced the task of constructing their relationship with the medical profession. Should this construction process be described as a conflict of values, a conflict of powers, or simply as a confrontation between experiences? It was probably more than merely a conflict of values. For one thing, AIDS was new to the medical profession along with the rest of society. In countries where the disease chiefly affected the "4 H's" (homosexuals, heroin addicts, hemophiliacs, and Haitians), the medical profession shared the same prejudices as the rest of society, if not more, against the first two categories of patients and their lifestyle choices. The medical profession underestimated the severity, the spread, and the urgency of the disease. Traditionally, epidemics had been managed by authoritarian, discriminatory means, through quarantines and bans, etc. The patients imposed respect for their rights, including their right to information. Until medical research came up with new molecules and assumed the initiative again, patients occupied a unique space for collective initiative. They weighed in on drug trials, the price of the drugs, homosexuality, drug addiction, etc. Now, the whole of society is confronted by these conflicts of values, powers, and the confrontation of experience.

What we talk about when we talk about ethics?

John D. LANTOS, MD, Director Children's Mercy Bioethics Center, Kansas-City, USA

This paper begins with a common dilemma – parents of a severely impaired baby request the withdrawal of life-sustaining fluid and nutrition. The staff members of the neonatal intensive care unit disagree about whether it is ethically appropriate to honor the parents' request. I analyze the ways in which the health care professionals think about and talk about the parents' request and the way that they justify their conclusions about the proper course of action. I argue that people's moral intuitions are pre-rational, that is, they do not reason to a conclusion but, instead, offer reasons to support their deeply felt but unanalyzed moral convictions. Drawing on meta-ethical theories of McIntyre, Elliott, and Kolakowski, as well as Haidt's arguments empirical work in moral psychology, I suggest that the purpose of conversation about controversial ethical issues is to shape and reshape our moral intuitions. I compare such discussions about ethics to the discussions about love in Raymond Carver's story, "What we talk about when we talk about love." Both ethics and love are supremely important domains of human flourishing. Both allow for widely variable responses to questions about their fundamental nature. In both, our ideas about what is good, natural, true, desirable or essential are constantly tested against constantly changing realities. Both must be understood interpersonally, through conversations that shape and reshape moral communities.

The many faces of medical integrity: adjusting to patients' values

Marta SPRANZI, PhD, Associate professor in history and philosophy of science, University of Versailles St-Quentin-en-Yvelines, Centre d'éthique clinique, Cochin Hospital – AP-HP, Paris, France

Patients' values and choices can come into conflict with healthcare professionals' own values. This is especially true for positive as opposed to liberty rights: a service to which a patient has a right to, must be provided by healthcare professionals. They can decline individually as long as they can transfer the patient to a colleague. Special provision for conscientious objection on the basis of healthcare professionals' subjective values is allowed. However, what if it is professional rather than personal values which are at stake? What if what the patient demands go against the healthcare professional's own view of what she owes to patients in general? This is often the case, as for example for requests for futile care. Or again for unconventional requests for assisted reproductive technology (ART) : « My job is not to create grandparents » affirms a ART doctor faced with a procreation request from an older patient. This is all the more true when doctors' objections concern common rather than new controversial practices. In these cases the conscientious objection model of conflict resolution is not sufficient. The law and professional standards are useful but insufficient. At best, they define policies and practices, but in dealing with single cases there is always a moral residue which has to be filled in by ethical reasons. In this presentation I will give a provisional definition of « professional integrity ». It has been argued convincingly that its content can evolve with societal changes and can thus naturally adjust to patients' new requests. But this is not the whole story. I would like to show that the way doctors understand their moral integrity also depends on the specialty they work in. Moreover, the frontier between personal and professional values is less clear-cut than it is often taken to be. Thus a doctor's moral integrity is a patchwork of different interconnected values: professional, contextual and personal. Moreover, such values are malleable and can be adjusted, to a certain extent at least, to the situation and the patient at hand. Following an effort for mutual understanding a real encounter can occur: when motivations and personal values are mutually understood and shared, professional integrity is upheld and patients' requests are not seen as excessive and/or outlandish.

10h30-11h00 COFFEE BREAK

11h00-11h30 PARALLEL SESSION (3)

ROOM 1: Patient's voice in the French health care system

Chair : **Claire COMPAGNON,** Patients' representative, Européen Georges Pompidou Hospital, AP-HP, Paris, France

Can ethical provisions be regulated by law? The case of informing a patient's kin when a genetic anomaly is diagnosed in the patient

Catherine AVANZINI, Patients advocacy, Alliance for Rare Diseases, Paris, France

The law on bioethics dated July 7, 2011 contains a provision that the patient's kin be informed of the findings of a genetic profiling examination. Before the person undergoes the examination, he is informed of the obligation incumbent upon him to inform family members of any serious genetic anomaly, as long as prevention or treatment measures for it exist, or a genetics consultation is available. If the patient is unwilling to inform his kin himself, he can ask his doctor to make them aware of any genetic information that is liable to affect them. At that point, they are invited to make an appointment for a genetics consult. This legal provision reinforces an article from an earlier law on bioethics that has not been applied. It was stipulated by decree dated June 20, 2013. The new provision raises many ethical questions. From the viewpoint of the patient: what becomes of the patient's freedom to experience his disease "as he wishes," if he is now obligated to inform his kin? The situation may limit patient autonomy in that the patient's only choices are to refuse to undergo the examination, in which case he is liable to forgo treatment for lack of a diagnosis, or to be the person who brings the bad news of a possible anomaly to all of his kin. What about respect for medical privacy? It is easy for family members to identify a person who is often ill and/or hospitalized. Isn't there some risk that this person will become "he who brings misfortune," even though it is not his fault that he inherited a genetic anomaly? Should he refuse to inform his kin, how will his liability be engaged? What impact will his refusal have on intra familial relationships? From the viewpoint of the patient's relatives, there is a dilemma between the right to know, in order to prevent the consequences of a severe genetic disease by taking measures to treat it and organizing one's private life and career as a function of the disease; the right to be unaware that one carries a serious genetic anomaly. From a more general perspective, here are a few of the questions we raised: Is beneficence to the family (and, by the way, terms like "patient's kin" must be defined) the same as beneficence to patients? What about the impact on intra familial relationships? What ethical conditions must be respected to make sure this information is beneficent to the patient and his relatives? What sort of support can be provided for the patient and his family through this ordeal? Is the procedure set up by decree ethical? It consists of sending a letter (the model for which was stipulated by decree). Perhaps this is not the best option. How will the people who discover this alarming letter react? They too may be planning to have children. Will the resources be available to provide support for all these relatives, who are liable to ask for an appointment with a genetics consultant? Will French justice have real and equitable access to this provision, all over French territory? The law mentions certain organizations that may provide counseling. What is their role and scope of competence? Will doctors adhere to this system? Our talk will be based on the experience of associations that have been confronted with these situations.

The "Etats Généraux" for kidney survey: the distress of patients undergoing treatment for terminal renal insufficiency

Christian BAUDELOT, Sociologist, Vice-president, Renaloo, Paris, France

Within the framework of the "Etats Généraux for kidney (diseases), an 18-month event in 2012-2013 that assembled patients, healthcare providers, and institutions, we carried out an ambitious survey to explore the impact of kidney disease on every dimension of the patients' lives. Method: The questionnaire was drafted by a stakeholder team meeting as a scientific committee. Its goal was to identify the problems people encounter, concerning both the medical treatment of their disease and the many other important areas of their lives: morale and well-being, integration in society, jobs and career, leisure time and holidays, relations with others, love life, assistance and support, mobility, and insurance coverage. An open question at the end of the questionnaire invited patients to express themselves freely on "the pros and cons of kidney disease treatment" and the improvements they'd like to see. The survey took 20 to 30 minutes to complete. 70,000 questionnaires were printed and distributed in French kidney clinics (along with a postage-paid return envelope). An online questionnaire was also set up, linked to patient community sites and forums, and promoted on social-networking sites. The survey period lasted for six months, from July to December 2012. Results: patient participation was excellent. 8,600 questionnaires were returned, 6,185 of them on paper and 2,415 online. About one in five of the respondents (N=1850) were patients in pre-terminal renal insufficiency. Over one tenth of the population of patients with terminal kidney disease (a total of about 70,000 patients) participated in the survey. The gender of the respondents matched the distribution reported in the Rein et Cristal registries: 60% male and 40% female. The age structure of respondents also reflected that of Rein et Cristal registry, in dialysis and transplant. Many patients (N=2400) seized the opportunity to express themselves on the open question, sometimes adding several extra pages of commentary to the questionnaire. Discussion and conclusion: As measured by the survey, patient well-being is comprised of a combination of physical factors (health today and trends over the past twelve months), psychosocial ones (the feeling they lead a normal life), and psychological ones (disease-related feelings like fatigue, pain, sadness, the feeling that life is ruined). The findings show that the morale of patients living with kidney disease is extremely low. Fewer than 50% feel they live normal lives, and nearly 50% reported that they feel health problems are ruining their lives. Patients treated with dialysis or grafts show a severe deficit in the field of job-market integration. Whereas, in the general public, more than 90% of men aged 25 to 49 years are working, that is true of less than 60% of TRI patients. These findings, combined with the commentary the patients wrote themselves in response to the open question, paint a bleak picture of kidney diseases, especially in the end stage. Kidney pathologies are silent killers, less familiar to the public than cancer or HIV. They ravage every aspect of the lives of the people they affect, in terms of emotional and psychological well-being, at home and in their careers.

Induced abortion: how a request for medical care can turn into an obstacle course

Véronique BOINQUET, MD, Clinical Ethics Consultation, Nantes University Hospital, Nantes, France

In France as well as in 57 other countries in the world, induced abortion is acknowledged as medical care for women. This type of care is singular since it is regulated by law. The spirit of the law is that women have a right of self-determination over their own bodies, and thus are the ones who initiate the abortion request process. They possess such freedom, but with a time limit. Through the context of abortion, the provider-patient relationship is modified in that the qualified center receiving women must be a mere service provider. This is unusual compared with standard procedure where it is up to the doctor to determine whether care is relevant for a given patient. Patients' and carers' values may even differ or diverge, but it is actually the women who must be proactive regarding the care they receive, while ideally being able to choose how it is conducted. They are under no obligation to justify their reasons. It therefore up to carers to acknowledge women's autonomy, accept their own values and receive, follow and adequately help women requesting abortion. Yet, the means necessary to carry out the best conditions of access to abortion are not necessarily implemented. Numerous obstacles impede such access: length of time before appointments, distance from the care center, constraints and restrictions regarding methods … It is worth noting some reluctance to include abortion among care easily available, including – increasingly so – in public hospitals. It seems to be relegated to a lower priority by health authorities and hospital heads, triggering the closure of many local abortion centers. The medical procedure is seldom performed by gynecologists and GPs, who resort – sometimes inappropriately – to conscientious objection and lack proper financial, social and peer recognition. Besides, common misconceptions about abortion – about psychological or physical impact, or even the alleged irresponsible behavior associated with the procedure – do not help to create an environment which is conducive to its implementation. Nevertheless, making abortion available on demand testifies to a positive evolution as a precursor to a benevolent secular society aiming at the fulfillment of individuals, acknowledging their own autonomy, advocating gender equity and emphasizing the prevention of suffering, diseases and violence. Access to abortion represents a priority objective for WHO regarding women's heath, while roughly 40% of women worldwide have a very restricted access to safe and legal abortion – or none at all. Ethical reflection about abortion may once more emphasize the humanist, philosophical implications linked with this right of women, universal in scope, and permit to remain vigilant to ensure that all women, particularly in precarious conditions, may access it safely and easily.

A patient's voice

Daniel CARRE, Patients' representative, ADMD (Association for dying in Dignity), CISS (Intersociety Committee for Healthcare), Paris, France

Making the patient's voice heard: this talk assumes all of the subjective and partial aspects of such speech. I am speaking on a personal basis alone: no one has mandated me to make a study, and I have no intention of researching the matter further. I am speaking freely. My relationship to my staff: I delight in the opportunity offered by this conference, because the patient's voice is so hard to hear. He waits good-naturedly in the waiting room, reading insipid, dog-eared magazines. If the wait becomes unendurably long, the impatient patient will vent his rage loudly, shouting insults at anyone within hearing, under the gloomy eye of the receptionist at the desk (a slice of life from the ER at a Paris public hospital). I am endowed with a great privilege: mastery of speech and one-on-one dialogue. The caregiver will not overpower my independence with his expertise, despite asymmetry of the dialogue between the learned person and the patient. Very quickly, the interview becomes an exchange, with both of us asking and answering questions. I ask to see a doctor, because I have noticed certain symptoms, or because all of the chronic disorders from which I suffer at the venerable age of 80 require periodic check-ups. I have already diagnosed my problem to some degree, on the basis of these symptoms, and expect the professional to confirm or reject it. As for the ongoing treatment, I manage it on the basis of test results. I monitor my own health, but of course, my work requires periodic evaluation. I am aware of the impact of my behavior on that of the caregiver, who must adapt to an informed, "brainy" patient, as my GP calls me. I demand to be in charge of my own health, and I choose my doctors as a function of this wish. I respect their skills and their ability to listen, so that everything proceeds harmoniously. My relationship to the end of my life: I have observed a gradual decline in my physical and intellectual capacities. Currently, I mourn the little things I have had to give up: I walk 7 miles instead of 12, climb only 1500 feet in altitude instead of 2400, play 9 holes of golf instead of 18. Likewise, I must mourn the loss of my ambition to be able to do anything, while maintaining a utopian desire to have an influence on the course of events. Like everyone, I am apprehensive about dying. I look for ways to prepare for death and tame it without sinking into depression, taking refuge in denial, or locking myself in obsession. In the few years I have left to live, I am worried about entering into a gray zone where high-tech treatment protocols are set up, where life turns into survival, where a chemical straitjacket hides anxiety. This gray zone is devoid of all desire, even the desire to fight decay. It is a gray zone where the patient surrenders to a healthcare system that lacks the capacity to prepare for death, and prefers to postpone it. My wish remains, to be in control of my fate: so I must anticipate death as much as I can. My goal is to leave a clear image, and therefore I am hoping to be conscious of when I have reached the point of no return. That point will come when I am struck by a violent illness that nevertheless fails to cause death. That point will come when my vitality and delight in life are gradually disappearing. Then, I ask that the healthcare professionals relieve my pains with compassion and let me make my final exit slowly, if I am not suffering, or assist me in dying if I express that wish – surrounded by all of my loved ones as I go. A trusting relationship with my caregivers provides me with valuable support. My doctors have my advance directives on file, and they know I have signed a durable power of attorney, deedsd that are designed to guarantee that my last days, coming closer every day, will be as pleasant as possible. In this way, an implicit contract has been drafted for the last treatment, if necessary.

Do patients have all the rights?

Jean PELLETIER, Patients' Representative, Paris, France

For centuries, hospitals have held sway over patients and their families. In 2002, French Health Minister Bernard Kouchner's "Patient Charter" at last acknowledged patient rights. The Charter was drafted in the course of a whole series of estates-general held by the minister and his staff. For the first time, people spoke freely, the heart of the issues was exposed, and progress was made. A few years later, the Senate's Léonetti Law, passed on April 22, 2005, established a framework for the rights of patients at the end of life. Current French president François Hollande has promised to form a committee to draft legislation going even further in this direction, on the basis of the Sicard report. Patient organizations, particularly the community of HIV patients, have mobilized public opinion to "impose" a new patient-doctor relationship on hospitals. Lastly, the Health Ministry department DGOS (Direction Générale de l'Offre de Soins) has recently implemented patient surveys to come up with an indicator measuring the satisfaction of patients hospitalized in obstetrics-gynecology units of 1300 public and private hospitals and clinics. This is a first, the outcome of an initiative that started in 2011. The issues: In part, this recent but real movement provides individual patients with more comfort and security, but the impact is measurable and felt on much broader levels. For example, patients' self-help organizations are thriving on the increased oxygen. There are many examples. The activism of people living with AIDS is notable, but they are not the only group that is represented. Regulatory legislation exists, and the institutions that manage French healthcare are beginning to integrate patients' qualitative demands, in the context of a severe and vigorous economic re-ordering within the field of hospitalization. Economic recession, current reforms, and medical progress: all these factors are uniting to amplify the patient's voice. This raises many major issues. The Doctor/Patient relationship is in search of balance. Should patients be granted even more rights? The answer is yes, but how far can patient advocacy organizations go? Isn't there some risk that a conflict will ensue, between the rights of patients and the duties of healthcare personnel? Patients basically demand transparency, information, and respect. However, it is up to them and their representatives to determine where the cursor will go on the scale of these values. A wise choice will only enhance their credibility, but it will depend on sound intellectual evaluation of the issues. The dialogue is engaged, and it is an opportunity for both patients and healthcare personnel.

The future of patient power

Christian SAOUT, President, Association Cooperation Patients, Bernis, France

The French law of March 4, 2002 on the rights of patients identifies them as "users" of the healthcare system rather than "patients." This choice of words has some bearing on what has been called "patient power." Patient power does exist. It merely demands to be claimed, in the relationship between the individual to healthcare providers and in the relationship to public and private healthcare facilities. With regard to the person, this power asserts the rights of the individual as the sole authority entitled to make his own personal choices, including decisions concerning health care. Access to knowledge by education and via new information and communication technologies has increased this power considerably. In relation to healthcare institutions, three struggles have highlighted "patient" mobilization: the fight against AIDS, the fight against nosocomial diseases, and the battle to conquer rare diseases. Undoubtedly, the "AIDS years" were the beginning of the period when patient power came into its own. In France, governmental authorities took action on the issue by inviting stakeholders to the Healthcare Estates-General in 1998. It led to the legislation dated March 4, 2002. However, today, "patient power" is about to be supplanted by "user" or "consumer power," as though the issues specific to the doctor-patient relationship or, more generally, the treatment dynamic itself, were of lesser importance. This is not the case. It would be absurd to limit concerns about the future of the French health care system to organizational questions (medical "deserts," treatment coordination, etc.) or financial ones (deductibles, access to complementary coverage, etc.). Significant issues persist, regarding the resources available to the healthcare provider/providee relationship to cope with the explosion of chronic diseases, as well as the reinforcement of the patient's abilities in coping with a long life with disease. Likewise, new questions have been raised by predictive medicine and various new medical practices. Nevertheless, after a brief flowering of "patient power," the first decade of the 21st century seems to have been devoid of mobilization. For example, the latest public-health scandals have not driven a new generation to unite and take action. Was "patient power" poorly served by the 2002 law and the contrasting ways it has been received by successive administrations? Is it the victim of its own turpitude? "Patient power" has lost its traction with medical officers, elites, and public officials. However, it has also failed to keep its promises. It has been slow to sift the knowledge acquired; it has shattered into myriad, poorly-defined organizations, and it has resisted the deployment of services. None of these failures are inevitable, if one continues to believe in the legitimacy and effects of patient power. The efforts that must be made are the reverse image of the unkept promises: think and then speak out; unite in order to help; transform the system to improve it. Because this conference is an opportunity to expose and confront international experiences, it is a boon to those promoting more determined "patient power" in France. New challenges face medicine. Masses of people will be affected by chronic illness, resulting in relational issues and questions of patient autonomy. Likewise, new medical practices like personalized, predictive or reparative medicine raise new ethical issues. These justify the reinforcement of "patient power," not its effacement.

ROOM 2: Clinical ethics and psychiatry

Chair: **Stella REITER-THEIL,** Psychologist, Professor of medical ethics, Basel, Switzerland

Problems of Clinical Insight When Listening to the Voice of Psychiatric Patients

Laura GUIDRY-GRIMES, Philosophy Doctoral candidate, Teaching Associate, Georgetown University, Arlington, USA

A primary issue within psychiatric ethics is the paternalism that can take over the physician-patient relationship. Concerns about not having their voice heard can result in patients' distrust of clinicians or the mental health system, which in turn can hurt treatment compliance. Psychiatric conditions vary widely in how they affect individuals, so it is dangerous to lump all of these patients together when making broad judgments about their inability to speak for themselves. All agents need sufficient knowledge of who they are and their situation in order to be self-determining and to make accurate subjective reports; however, which knowledge is necessary and how much knowledge counts as sufficient are debatable. Mental health literature refers to this knowledge as clinical insight. The question of whether a patient has insight is among the first to be considered in psychiatric contexts. There are several competing conceptions of insight, and data on which groups of patients tend to lack insight have changed dramatically over the years. In 1973, the World Health Organization worked with a conservative standard: patients only had to show awareness of some emotional illness without identifying specific signs or symptoms. Most accounts, however, have much more demanding criteria. Insight used to be considered all-or-nothing and unidimensional. Currently, insight is viewed more as a multidimensional and continuous construct. The precise specifications of the dimensions appear inadequate for providing clear guidance, however. Moreover, studies give contradictory evidence regarding the frequency and consequences of poor insight. For example, some researchers claim that all psychiatric conditions compromise insight; others suggest that psychotic conditions are distinct in having poor insight as one of the necessary symptoms. Whereas some research shows that the minority of people with Schizophrenia lack insight, other research shows that the majority lack it. Several studies find no correlation between level of insight and severity of psychopathology, but others come to the opposite conclusion. A number of crucial questions remain unanswered or fiercely debated. What counts as proper acknowledgement or awareness of illness? How must the individual describe her experiences? What if he/she avoids certain clinical terms but nonetheless seeks psychiatric assistance? It is common for physicians to believe that insight has to be a goal of treatment, since insight aids compliance with medication and can prevent involuntary hospitalizations. There is a potential circularity concern here, however. If 'insight' is interpreted as the willingness to accept medical labels and treatment, then this phenomenon will only show up for patients who are compliant and who voluntarily admit themselves to psychiatric treatment. Given the conceptual ambiguities associated with insight determinations, there are significant ethical concerns about how much weight a patient's voice ought to be given in psychiatric care. On the one hand, denying a patient's voice when she has sufficient insight will be morally costly; on the other, falsely assuming a patient understands her condition and the purpose of treatment can be harmful as well. Clinical ethics support services can contribute to ongoing discussions on how to respond respectfully and appropriately to the voices of psychiatric patients, especially in cases where insight is unknown or unclear.

When the patient's voice is overruled. Ethical challenges and coercion in mental health care. A qualitative study of health care personnel

Marit Helene HEM, Researcher on Medical Ethics, Oslo University, Faculty of Medicine, Institute of Health and Society, Centre for Medical Ethics, Oslo, Norway

Background and aims: In recent years, there has been increased attention on the use of coercion in mental health care. To our knowledge, there are only a few studies that focus explicitly on the ethical dimension of coercion in mental health care. The use of coercion is a complicated moral enterprise which deserves to be systematically examined. The aim of this paper is to explore what kind of ethical challenges and dilemmas mental health care personnel face in connection with the use of coercion. Methods: We conducted seven group interviews in three institutions involving 65 participants (psychiatrists, psychologists, residents, nurses, nursing assistants, social educators) from a broad range of clinical fields within mental health services (acute wards, rehabilitation unit, adolescent psychiatry, geriatric psychiatry, outpatient services). We asked the participants to explore ethical dilemmas and challenges related to the use of coercion (formal or informal), for example situations where they had doubts about whether or not coercion should be used, and why it felt wrong, or morally sound. The interviews were tape recorded and transcribed verbatim (200 pages). The analysis is inspired by the concept of 'bricolage' (Kvale and Brinkmann 2009, Tanggaard and Brinkmann 2010). We moved freely back and forth in the data material without relying on specific methods and analytical techniques. It is an eclectic way of making sense of the data material. Results: Participants have a broad and varied view on coercion, and include both formal and informal coercion, as well as perceived coercion. They say that what is defined as coercion already involves moral judgments. The concept of freedom is perceived as important to understand the concept of coercion. The participants describe that coercion may be needed in order "to position" themselves to help the patient. The possibility to use coercion is then considered as "a necessary evil". Coercion provides an opportunity to intervene in the patient's life. They put paternalism against neglect, and describe how coercion involves a balancing between the two. Some view coercion in light of the potentially infringing culture of mental health care that already appears in the distinction between "us and them". Furthermore, several describe ethical challenges concerning informal coercion relating to following rules for daily life in the department, e.g. in connection with meals, bedtimes and use of smart phones. Others mention the ethical dimension of how coercion is performed/executed, and the patients' perceptions of the situation. Disagreement between staff members is mentioned as a possible cause of abuse of coercion. Some ethical challenges related to coercion seems to be context-specific – e.g. depending on whether it is acute, geriatric, rehabilitation, youth or outpatient settings - while others seem to be common across different contexts. Discussion: This study reveals many different kinds of ethical challenges in connection to the use of coercion. Different contexts may bring forth different kinds of ethical challenges. The ethics of informal coercion and perceived coercion is considered as important as formal coercion. Defining coercion is a moral challenge in itself. Two topics seem to be relatively unexplored: how to meet and cooperate with relatives, and what kind of patient participation in coercion is appropriate.

Talking With the Patient; Not About Him Clinical ethics consultation in psychiatric settings

Klaus KOBERT, Clinical Ethicist, Bielefeld Evangelic Hospital, Bielefeld, Germany

Within the last decade, Clinical Ethics Consultation (CEC) has gained increasing importance in Europe. Up to now, the consultation activities focus mainly on somatic medicine, therefore there is little experience in the area of psychiatry. Questions like "Are there special needs of clinicians in a psychiatric setting concerning CEC?", "Are there specific values which influence and modulate a case discussion?" and "Should psychiatric patients actively participate in a CEC?" are not answered yet. To investigate these questions, the data of about 280 detailed records of CECs performed in the years 2006-2012 in our hospitals, including 12% of records of psychiatric wards were analyzed. Additionally, we evaluate the results obtained through a questionnaire that were distributed to the staff members of the psychiatric wards. We do this in order to validate the results of the retrospective evaluation and to examine the particular circumstances resp. conditions for psychiatric patients to participate in a CEC. To deepen the gained results about the conditions of CEC in psychiatric settings and the patient's role, we carried out semi-structured interviews with staff members of the psychiatric wards. Our data shows that patients with psychiatric disorders take significantly more often an active part in CEC than patients with somatic diseases. That is highly appreciated by the staff members. For a successful process of decision making under these circumstances several terms have to be arranged. Targeted measures to support and empower the patient in this course of action are identified. Results of the evaluation will be presented and consequences for clinical ethics consultation will be discussed.

"Il faut reculer pour mieux sauter": strengthening the participation of a patient advisory board in mental health care

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This contribution discusses a clinical ethics consultation project in which two ethicists (VU Medical Center) facilitated a deliberation process of the patient advisory board of a large mental health care institution in The Netherlands. The objective of this deliberation process: to strengthen this patient advisory board and to increase its self-awareness in order to confront current challenges in Dutch mental health care. Since 1996, health care institutions in The Netherlands are obliged by law to have a patient advisory board. This board maintains the right to be properly informed, to meet with the board of directors of the institution, to advise, to decide over board members, and to deal with complaints. Currently, legislation is proposed to even increase the right of patient advisory boards to take part in decision making processes. However, although the participation of patients in the organization of care is now enforced by law, other forces are still obstructing this participation. As the patients we worked with reported, among these forces are: a lack of self-awareness, vision and mission; not being taken serious by the board of directors and other deliberation partners; challenges concerning the mental health status of the board members; a lack of skills in exerting influence. In 2012, the patient advisory board of a large mental health care institution approached us to support a (self-) reflection and deliberation process by means of which they sought to deal with these obstructing forces. Primarily, they felt this need against the backdrop of recent developments in policy (such as the proposed legislation) and impending rigorous cuts in mental health care. During the course of 2012 and 2013, we supported this reflection process by facilitating dialogues based on the principles of moral case deliberation. A moral case deliberation is a reflective dialogue, in which, through a structured method, a concrete moral issue is analyzed in order to come to a shared moral perspective and to agree upon courses of action. This dialogue is moderated by an ethicist, who acts as a facilitator of the joint reflection. It is based on the participation, moral knowledge and responsibility of the participants themselves, usually health care professionals. In a series of meetings, two ethicists and the patient board deliberated on both practical and ethical questions raised by the members of the advisory board, such as: • What is the profile of a good patient advisory board member? • What are our strengths and weaknesses? • How should we deal with the vulnerability of our members? • How to boost our impact in decision making processes? • Should we primarily focus on financial matters or should we deal with good care as such? In a final meeting, we evaluated the outcomes of the reflection process as a whole. Together, we sought to translate them in a vision and mission of the advisory board, and we assessed what they meant for concrete courses of action in the near future. In general, participants agreed that the project had boosted confidence and self-awareness and had provided them with instrumental insights in how to make their voices heard. As one of the patient members remarked: il faut reculer pour mieux sauter – we had to take a step back (and reflect) in order to make a better jump forwards. Finally, we will address the specificities (advantages, challenges) of moral case deliberation with patients only.

Family members' views on coercion and involvement in mental health care: some ethical dilemmas and challenges

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Some of the most important ethical challenges in mental health care are tied to the use of coercion. The project "Mental health care, ethics and coercion" aims at gathering more knowledge about these challenges and to strengthen ethical reflection in mental health care. This presentation will discuss some results from a qualitative narrative study exploring family members' views on experiences with coercion and involvement in patient care. Qualitative interviews were conducted with 20 family members to adult patients from next of kin's -organizations and 16 family members to young patients from hospitals in Norway. Analysis shows that relatives have complex and partly conflicting moral views on coercion. Ethical dilemmas are seen in a broad perspective, relating to disruption of biography, everyday life treatment quality and interactions with mental health services. Many relatives experience too little involvement, often as a result of staff's views on patient confidentiality. However there is also reluctance towards being involved. Further, ethical challenges occur in relation to power dynamics; both powerlessness due to lack of knowledge or involvement and power due to the possibility of initiating coercion from the mental health system. In conclusion, the study shows that ethical dilemmas and challenges regarding coercion and involvement of family members in patient care are complex phenomena. Family members can be the patient representative, but also may have different views on coercion than the patient. Many stories confirm, however, a general lack of involvement of family members in mental health care. Family members experience that their voices are not heard or included in care. Implication of findings for clinical ethics consultations will be discussed.

Ethics Consultation (EC) in Forensic Psychiatry (FP): a case study on "chemical castration"

Stella REITER-THEIL, Medical Ethics Professor, Co-founder ICCEC, Basel, Switzerland

Little is known about the practice of Psychiatric Ethics Consultation. This is surprising as (Forensic) Psychiatry displays a great variety of pressing ethical issues in daily care. Recently, a major psychiatric institution has asked for and institutionalized Clinical Ethics Support (CES). Case study on an EC from the perspectives of the physician in charge and the ethics consultant; ethical evaluation of arguments and approach of EC will be discussed. The ethical permissibility of the "chemical castration" of a sexual offender with reduced decisional capacity due to mental retardation. "Chemical castration" is a pharmacological intervention aiming at the reduction of the patient's sexual activity (erection and sexual phantasies decrease); the medication can lead to osteoporosis, weight gain and other physical changes (feminization). Exploration and analysis of pros and cons of 2 options: 1. Chemical castration is ethically justified. Main argument: The patient can be allowed to live in an open institution, rather than in a closed one, or in a private setting if the prognosis of sexual offense is significantly reduced. 2. Chemical castration is ethically not justified. Main arguments: The intervention violates human dignity and the patient has no full decisional capacity due to mental retardation. Results It is still rare that EC is initiated from the patient's or relatives' side; this EC was initiated on the request of the legal substitute of the patient who initially disagreed with the treatment plan proposed by the clinical team. Thus, besides several interdisciplinary aspects, the views of the patient's legal substitute had to be taken into account including her in the decisional processes. The EC led to clear results: On the basis of the systematic exploration and analysis of the pros and cons of the 2 options an agreement was built for option 1: despite certain risks and side-effects, chemical castration would help to improve the patient's quality of life allowing for more independency. Without chemical castration, the patient would require being detained in closed, institutional settings. The requirement of close follow-up and continued re-evaluation was stated. Discussion As a process, the EC showed the following characteristics: It was initially clarified that decision-making on any interventions stayed with a) the clinical leadership and team, together with b) the legal substitute of the patient. Also, tasks and roles were clarified. The large group discussed collegially; concerns and hesitations of the legal substitute were taken seriously. Consensus-building proceeded step-wise with formulating explicit criteria necessary for ethical justification of initiating, maintaining and monitoring the medication. Retrospective evaluation: the legal substitute – the actual "client" of the EC – experienced an advantage by using the EC setting as compared to her previous discussions without EC; the clinical team appreciated the ethics support. Consensus might not have been reached without EC. Literature searches in databases identify only few references on CES/EC in Psychiatry and Forensic Psychiatry; thus, this case is innovative. Conclusion Due to the highly legalized context of FP and to the strongly established communication culture EC seems to be easily adjusted and adopted by leadership and staff.

ROOM 3: Politically sensitive contexts and the patients' voice

Chair: **Marie GAILLE,** Philosopher, Research Director, SPHERE, University Paris Diderot, Paris, France

The voice of the immigrant or precarious patient: communication difficulties and biases in the healthcare relationship

Jérémy GEERAERT, Sociology PhD Student, Paris 13 University, Aulnay-sous-bois, France

The point of this talk is to report on the difficulties associated with communication between doctors and migrant or precarious patients in the context of medical and social treatment provided by public hospitals. We carried out an empirical study of "PASS" hospital structures (Permanence d'Accès aux Soins de Santé, "Ongoing Health Care Access"), analyzing interviews and making observations during visits with doctors, nurses, and hospital social workers. Our findings emphasize the threefold barrier – cultural, social, and linguistic – encountered by immigrant or precarious populations seeking access to health care. The cultural barrier is inherent to the PASS patient population, immigrants who are moreover often very recent newcomers to French territory. The fact that they are such newcomers increases difficulties in understanding linked to cultural factors like codes regarding speaking of the body and of pain. The concept of somatization may be unknown. The social barrier arises due to the contrasts in the "habitus" of healthcare staff and patients. Unlike doctors, nurses, and social workers, the great majority of the patients live under extremely precarious economic or social conditions. Their way of life is stigmatized, making it difficult for them to impart certain details about their living conditions, despite the fact that these details are essential to effective medical and social care. The language barrier is undoubtedly the greatest obstacle in the health care relationship. Staff and patients do not speak the same mother tongue and, in most cases, share a common language only partially or not at all. Another theme of my talk is the description of how a specifically designed structure, made up of social workers, nurses, and general practitioners, has worked to overcome these three barriers, devising strategies to reduce or eliminate them. The program we have developed provides doctors, nurses, and social workers with an informal specialization in "treating precarity." It familiarizes them with the obstacles they are likely to encounter with this type of patient population. For example, they can create and set up resources (interpreters, online translation, closed-question questionnaires, etc.) that facilitate communication that was initially impossible. Practical know-how and familiarity with the patient population is the best way for health care professionals to be proactive, already aware of the facts of social life for immigrant and precarious patients that are decisive for treatment. Lastly, more generally, my talk intends to show how the PASS program and the professionals implementing it have structured a legitimate space for a certain type of communication, related to the health care relationship between people who do not share a language. This communication space is rare and innovative in the medical field. It operates according to rules independent of those of the medical linguistic market, and has advantages and drawbacks. Although it gives a certain category of patient access to treatment for the first time, it also makes the individual the captive of a device that is supposed to be transitory. The PASS program offers an innovative treatment arrangement adapted to the patient. However, it is confined to a structure that provides services to only a minority of the patients who lack access to healthcare due to communication problems.

Above and Beyond: Ethical Dilemmas in Treating Children Across Borders – A Joint Israeli Palestinian Mission

Efrat HARLEV-BRON, Deputy Director, Schneider Children's Medical Center, Petach Tikva, Israel

Schneider Children's Medical Center of Israel (SCMCI) is the only tertiary care hospital in the country. It is part of the public health system in Israel, providing care to all the Israeli population, Jews and Arabs, and is dedicated to the well-being of all children, irrespective of race, religion or nationality. Historically, Israel is in a state of conflict with the Palestinian Authority (PA), with times of war and times of peace negotiations. With no relevance to the political situation, children from the PA are referred to our hospital for complex medical situations that require high standard care. These referrals create a variety of challenges which include medical collaborations, communication between caregivers, economical agreements, cultural diversities, logistics, and above all – ethical aspects and dilemmas, which will be presented in this paper: 1.Prioritization of treatment and limited resource allocation. The public healthcare system in Israel has limited resources. Average occupancy at the SCMCI is 100%. This does not allow us to respond positively to all the referrals from the PA. Thus we must choose the referrals which are at the highest level of need for our expertise and with our highest ability to improve the patient's condition. These clinical definitions confront us with "grey areas" and ethical conflicts. We must always take into consideration the basic commitment for the Israeli population. Basically, under no condition, a Palestinian patient will take the place of the Israeli citizen. But reality forces us to face every day decisions of prioritizations. 2.Language and cultural diversities. Israel is known for its multicultural environment; The medical caregivers are familiar with the diversity of treating Jews coming from different Diasporas, Christians, Muslims, Druze and more. Nevertheless, treating the Palestinian children and the interaction with their parents challenge and arise new issues. These call for ethical solutions to allow the children and their parents to express themselves and to give voice to their preferences and values 3.Guardianship, informed consent and interpersonal communication. Often, a child will arrive to SCMCI accompanied by one parent or another relative. This brings to the center psychological problems as well as ethical and legal issues. The caregivers face conditions in which information regarding the child is not well communicated, and the decision making is influenced by the lack of physician-patient proper communication. 4.Medical decisions influenced by infrastructure disabilities. Due to the infrastructure of the PA's healthcare, continuity of care is not optimal, and sometimes leads to elongation of hospitalization. Moreover, the decisions for the chronic treatment of the child are sometimes influenced by the availability of treatment possibilities. Above and Beyond: While trying to find overall solutions to these issues,we established an conjoined initiation between SCMCI and the PA that is aimed to improve the pediatric care in the west bank, and to allow our caregivers a better understanding of the Palestinian families' preferences and culture. This conjoined project is based upon the basic belief that children are the innocent bystanders, and are Above and Beyond any conflict. Thus it is our responsibility to create a bridge over the medical, cultural and ethical challenges.

"So, you are a Nun?" Ethics Expertise Lost in Translation

Maureen KELLEY, Bioethics Associate Professor, Washington University, School of Medicine, Seattle, Washington, USA

As global health clinical and research initiatives have grown we have also seen an expansion of international partnerships, teaching, and consultation in clinical and research ethics, many between developed and developing countries. I'd like to suggest that we can learn something about the debate over foundations for clinical ethics expertise by reflecting on the usefulness of clinical ethics practice in settings where one's metaethical foundations and notions of moral authority are worlds apart. To illustrate this point, I will share highlights from an ongoing clinical ethics program between our university in Seattle and a district hospital in rural Uganda. Where, not surprisingly, the attribution of "ethics expert" in a setting where such designation is reserved for Priests, Nuns, and Elders, was met with confusion and discomfort (my own included). Stripping away any recognized claim to moral authority and lacking common ground on some substantive moral ideas and principles, we nonetheless have made headway on several perplexing and familiar ethical dilemmas. That is, against the clinical ethics expertise skeptics, we were able to meaningfully discuss and decide what ought to be done. Efforts like this suggest that debates over the foundations of moral judgments are philosophically important but practically unnecessary. At best, such debates in the field of clinical ethics are a distraction to the useful and difficult work of practical ethics, whose inner workings are not terribly mysterious: gathering the people in a position to address ethical problems, describing the ethical challenges at hand, identifying and prioritizing values, applying shared principles, reconciling conflicts or easing tensions through pragmatic solutions. At worst, such skepticism may have a chilling effect on opportunities for mutual learning and problem solving on matters of deep moral importance with international partners.

Ambiguities of a patient's wishes with altered mental status in the critical care setting: the case of an elderly man with respiratory failure

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Caring for patients with critical illness is often marked with ambiguities in hearing the patient's voice. Critically ill patients often suffer from cognitive states that render them unable to express themselves to family and caregivers, causing difficulty for the team to discern appropriate goals of care. This paper addresses one particular case of a critically ill patient in an ICU of a Harvard Medical School teaching hospital in which the patient's inability to express himself frustrated the team's efforts to discern good care for the patient. Debilitated by a recent course of pulmonary tuberculosis, recurrent aspirations leading to pneumonia, and congestive heart failure, the patient eventually suffered respiratory failure requiring chronic ventilatory support and artificial nutrition and hydration. While efforts to appreciate the patient's wishes seemed to indicate that the patient did not want to live on a ventilator and wanted to 'die naturally,' what the patient wanted was not entirely clear given: 1) the patient's altered mental status and lack of verbal interaction (beyond one or two word answers) made the team unconvinced about his capacity to make life or death decisions; 2) the patient's inability to communicate with the team outside his native Asian language, requiring exclusive reliance on an interpreter to communicate with the patient; and 3) disagreement with the patient's family about what the patient actually was saying when questioned by the interpreter, as the family insisted that the patient did want to live on ventilatory support no matter what the burden. Such a difficulty in communicating with this patient led to considerable frustration for the team, which felt as if the patient was subjected unwillingly to excessive treatment because his voice was not heard clearly enough. This case brings up several crucial questions involved in listening to the critically ill patient's voice, such as: What should be done when the patient's voice is not accessible to the team? How should contradictions between the patient's and family's wishes be mediated? How should the patient's voice be listened to when he or she comes from a culture that does not value autonomy as highly as in the west? These questions will be addressed in this paper using details presented by this particular case.

ROOM 4: Philosophical Foundations for Cess

Chair: **Georges AGICH,** Philosopher, Bioethicist, Texas, USA

What could make someone an ethics expert?

Mark SHEEHAN, Philosopher, The Ethox Centre, University of Oxford, Oxford, United Kingdom

In order for someone to be an expert in X there must be something that they know or can do that the rest of us, non-experts, cannot know or do. Alternatively, the expert in or at X is better at doing X or knows X better than non-experts. What matters here is that there must be a standard against which experts and non-experts are judged in order for us to talk of experts in that area. If there is no standard or no possibility of a standard there can be no experts. Expert problem solvers are better at solving problems than ordinary problem solvers. Expert counselors are expert in counseling and so on. In each case the possibility of their being experts in each domain rests entirely on there being a standard according to which the expert is better than the non-expert. In the case of ethical expertise, there is a range of ways for specifying the domain. We may say that the ethical expert is someone who is fluent in the arguments of moral philosophy or is someone who is adept at dissecting and constructing arguments for particular courses of action. However, in the context of ethics expertise, the centrally contested domain is the domain regarding what ought to be done or how things ought to proceed in any given situation. That is, the primary question is whether someone can be an expert in knowing what ought to be done or how things ought to proceed. Why is this specification the primary domain? If we consider other domains related to ethics, say knowledge of moral philosophy, we are quite happy to say that someone can be an expert in this domain without being an expert in knowing what ought to be done or how things ought to proceed. Moreover, when we think of expertise we are very close to questions of authority, legitimacy and justification. But when an individual has knowledge or ability in these other ethically-related domains, their expertise and, so their authority has limited practical force. That is, absent any argued connection between the two, the expert in Kantian moral philosophy is not an authority on what ought to be done or how things ought to proceed. This, we argue is true for all secondary domains in this area. That is, there are bodies of knowledge and sets of skills that are related to ethics but which do not, without substantial argument, amount to expertise of the kind that would make someone an expert in knowing what ought to be done or how things ought to proceed. Our claim in this paper is that in order for there to be experts in ethics (i.e. experts in knowing what ought to be done or how things ought to proceed) there must be a standard according to which we can, even in principle, measure experts against non-experts. We take it that providing this standard is equivalent to providing a claim about standards in ethics. It follows from this claim that someone claiming that there are ethics experts in the sense mentioned should provide an account of those standards and the reasons for thinking that the expert is in a better position to attain them than non-experts. This is not to say that clinical ethicists (or any other ethicists) have nothing important to contribute to the clinical setting. It is only to point out that without an account of the standard by which what ought to be done or how things ought to proceed is to be judged, it cannot be claimed that clinical ethicists are experts in knowing what ought to be done or how things ought to proceed. That is, they cannot claim to be ethics experts.

Ethical Expertise without Metaethical Foundations

Dien HO, Philosopher, Healthcare ethics, MCPHS University, Boston, USA

As clinical ethics consultations proliferate, an increasing chorus of critics including David Archard, Robert Burch, Christopher Cowley, Raymond Frey, Cheryl Noble, and Kevin Wildes have called into question the legitimacy of clinical ethicists and their professed expertise. One line of argument is that ethical expertise presupposes that those who possess it enjoy certain epistemic asymmetry; that is, they have ethical knowledge that non-expert do not have. Ethical knowledge, as the argument goes, is only possible if we accept certain metaethical views (e.g., moral realism: moral claims are factive). But since the relevant metaethical debates remain unresolved, to claim ethical expertise is premature at best and fraudulent at worst. If clinical ethicists do not possess any special knowledge, then it is difficult to justify their participation in clinical ethical consultations. In other words, why do we need ethicists, if they know no more than non-experts? In this paper, I challenge the premise that all forms of ethical expertise presuppose certain metaethical assumptions. To wit, the critics of ethical expertise wrongly construe the nature of clinical ethics consultations. Engaging in ethical discourse in order to locate the appropriate solutions to moral problems does not usually entail anything metaphysically robust. Suppose a friend comes to see me seeking advice on whether she should tell to her husband about a past affair. After an extended discussion, we conclude that it would not be morally wrong for her to withhold the information. It would be peculiar, to say the least, if she were to ask further, "I understand why it would not be wrong for me not to tell my husband about the affair but is the conclusion factually true?" The reason why the latter question strikes us as absurd is that in resolving ordinary ethical conflicts, we do not invoke any deep metaethical assumptions. The critics of ethical expertise understand ethical conflict resolution as akin to deriving correct moral conclusions from a set of deep normative principles. In reality, this is rarely the case. Just as an expert research biologist rarely concerns herself with the merit of scientific realism in her day-to-day research, an ethical expert can help us solve moral problems without first having to settle intractable metaethical debates. In the final section of my paper, I propose a theory of what we do when we attempt to solve microethical (to borrow a phrase from Bob Truog) problems in our everyday lives. Within this framework, ethicists can play an enormously helpful role in identifying and negotiating all the relevant conceptual issues. Moreover, advocating for patients' interests is not only morally permissible, it is morally obligatory in some instances.

"Ethics Expertise in the Face of Metaethical Agnosticism," part of a panel "Does Ethics Expertise Require a Metaethical Foundation?"

Lisa RASMUSSEN, Philosopher, University of North Carolina, Charlotte, USA

What would justify a claim of an 'ethics expert' about what ought to be done in a particular situation? This question, at the heart of debates over ethics expertise in clinical ethics consultation and other 'applied' areas of moral philosophy, requires a step to the meta-level. It is a question of what one understands to constitute justification for a particular kind of claim. Moral philosophy often assumes that a justification of a claim of "knowing what ought to be done" requires a metaethical justification. However, why restrict "knowing what ought to be done" to a strictly metaethical interpretation? If we merely equate "knowing what ought to be done" with "knowing what is justified by a metaethical position", then it begs the question or is simply stipulative. If, on the other hand, there are other means of justifying "knowing what ought to be done" claims, then there is no automatic answer to the title question of our panel. I argue that a) knowing what ought to be done in a clinical ethics consultation situation is an all-things-considered view which b) does not constitute a 'theory' because there is no systematicity to it, and which therefore c) is not supported by a metaethical foundation. It is a "muddling-through" approach that a) challenges the claim that judgments about "what ought to be done" by definition require metaethical foundations, and b) points out the difficulties with asserting judgments based on contested metaethical positions (e.g., that even if we subscribe to a demand for metaethical foundations, given the radical disagreement and epistemological uncertainty about such foundations, they are themselves impossible to deploy in judgments about clinical ethics consultation).

Ethics expertise in public policy-making: between democratic rule and moral reasoning

Kyle EDWARDS, PhD Student, Ethox Centre, Nuffield Department of Population Health, University of Oxford, Oxford, United Kingdom

Much of the current debate on ethics expertise relies on explicit or implicit metaethical commitments concerning, for example, whether moral truth exists and whether ethics experts have privileged access to it. This debate also connects to other related questions about the role that should be given to 'lay experts', and the extent to which the voices of patients or carers should be heard, in ethical decision-making. This paper argues that we can usefully move beyond these fairly entrenched arguments by reframing the debate upon the particular role of ethics expertise in a specific socio-political context. By drawing on concepts of authority and legitimacy central to political philosophy, we flesh out the role of the ethics expert in public policy-making in liberal democracies. Specifically, we examine the tension between democratic rule and moral reasoning, which liberal democracies manage by creating a sphere of 'liberties' over which majority rule cannot prevail. Beyond this sphere lies the realm of 'legitimate coercion', where the democratic state is justified in placing limits upon, and making demands of, its citizens. We explain the role that the ethics expert can play in clarifying the limits of legitimate coercion, and in identifying salient characteristics of a particular issue – such as rationing healthcare or using reproductive technologies – in order to determine whether it falls within or beyond these limits. Whilst we concede that at the abstract level where moral and political philosophy meet our reframing remains open to metaethical challenge, we contend that it can provide practical steps forward in the ethics expertise debate by specifying a clear and justified account of the ethics expert. The argument we develop also has important consequences for clarifying the concepts of 'patient and public involvement' and 'stakeholder representation', which lie at the heart of contemporary scholarship about clinical ethics support roles.

The Absence of Consult Closure and the Cost to the Patient's Voice

Autumn FIESTER, PhD, Director, Penn Clinical Ethics Mediation Program, University of Pennsylvania, Philadelphia, USA

On the conventional practice of clinical ethics consultation, the consult ends when a "resolution" is reached, i.e., when the consultants "render a decision," "make a recommendation" or "fashion a plan." This narrow understanding of what constitutes the resolution of a clinical ethics consultation generates an ending but fails to achieve "closure": a "comforting or satisfying sense of finality." Consults without closure neglect the lingering aftermath for patients and their families, and, in effect, undercut their ability to voice their objections, reactions, dissent, priorities, values, desires and concerns. The consequence for patients and their families is a set of destructive moral residuals: moral distress and the moral emotions. To truly give voice to patients and families, consultants must not only resolve the actual ethical dilemma, but they must also resolve the difficult feelings of the participants that accompany any perception of moral offense, moral powerlessness, and moral difference. The predominant mode of ethics consultation has grim prospects for achieving this kind of closure because it short-cuts the indispensable process for how we work through our disagreements with others. Achieving genuine closure requires a consultant- assisted conversation that is the keystone of the approach to consultation called "bioethics mediation." Only with an opportunity for patients and families to participate in a candid dialogue with providers will they have a genuine voice in the resolution of values-based disputes at the bedside.

Hope – different conceptions expressed during ethics consultation

Gerald NEITZKE, Consultant in clinical ethics, Hannover Medical School (MHH), Hannover, Germany

Hope is a concept frequently encountered during ethics consultations. Physicians, nurses and particularly patients and their relatives often talk about individual ideas of hope in specific contexts. They use hope as an argument in decision making about therapeutic options. This way, hope becomes a normative category in clinical ethics and ethics consultation. Therefore it is useful for ethics consultants to learn more about different conceptions of hope, the ways in which medical staff and involved patients and relatives articulate hope, and techniques to inquire individual hopes during consultation. The presentation will argue that hope is a concept which includes a qualitative, a quantitative and a relational dimension. Physicians overestimate the qualitative dimension: A common notion in ethics consultation is that in a case in question there is either hope or the case is 'hopeless'. Apart from that, ethics consultation should encourage the quantitative dimension of hope: Many patients indicate that at a certain stage of their disease they have more or less hope. Beyond that, the presentation will show that the relational dimension is crucial in ethics consultations: What are the hopes of the patient in the situation given, what are they related to, what are the therapeutic aims the patient wants to strive for? Ethics consultants should support medical and nursing staff to listen to the language used by patients and next of kin concerning individual hopes and fears. It is crucial to realise that all patients, even terminally ill and dying patients, have a certain amount of hope concerning specific aims. Sometimes these hopes relate to healing, sometimes to life prolonging treatment, sometimes rather to aspects of quality of life, and sometimes to non medical, even transcendent wishes. In the context of ethics consultation autonomy and autonomous decisions play a predominant role. In order to support patients to make up their minds and express their wishes, hopes can serve as a bridging concept to better understand individual preferences and wishes. A four level model will be presented to sensitize ethics consultants to individual hopes. If a patient hopes for healing, other medical options will be advisable than in a situation, where patients primarily hope for an improvement of their quality of life. A frequent challenge in ethics consultation is the overestimation of patients' health expectations by physicians. One motivation of physicians to offer medical options, even if benefit and prognosis are disputable and doubtful, seems to be their assumed responsibility to maintain or to create hope. A differentiated and realistic view of hopes in patient care will help to conscientiously and honestly identify patient preferences. Therefore the conception of hope, presented in this paper, can support the moral quality of medical decision making. Finally, physicians and nurses can support realistic hopes and help patients to overcome unjustified hopes. Physicians' fears of a 'hopeless situation' become pointless.

ROOM 5: Qualitative research : the patient's voice as methodological tool

Chair: **François DE SINGLY,** Professor of Sociology, Paris-Descartes University, Paris, France

Qualitative research in psychiatry: an ideal means of access to the patient's voice

Anne REVAH-LEVY, Child psychiatrist, Centre de Soins Psychothérapeutiques de Transition pour Adolescents, Argenteuil Hospital, France / INSERM, Paris, France

This talk is an overview of our proposal to host a session centering on the theme of qualitative research. It is not a lecture as such, but a presentation of the session. Health and disease are complex phenomena, because they concern not only a physical condition but also a person, who experiences the changes in his health in a subjective, singular way. This is even more evident in the field of psychiatry, where subjective phenomena are at the center of the disease, and the subject undergoes a change in his entire being-in-the-world. The fact that we intend to address these subjects scientifically requires a research paradigm capable of reporting on the complexity of the experience, by probing the patient's perspective in all of its subtleties, without reducing the phenomenon to a limited number of measurable variables. Today, qualitative research has come into its own as the ideal method for the study of the subjectivity of experience. The exponential number of papers being published internationally attests to the medical world's increasing need to understand disease from a bio-psycho-social perspective. The qualitative method refers to a set of specific research methods (phenomenology, grounded theory, ethnography), which share an interest in understanding people's subjective experiences and perspective on story. The change in the paradigme in relation to traditional medical research is obvious, on the basis of these fundamental concepts: The nature of knowledge. The act of knowing is not independent of the person who knows: knowing is an interpretative process. Interest in individuality. We are not interested in the average or statistical subject, the way medicine is. Instead, we take an interest in the participant in the research. Likewise, instead of being studied, this person works with us to understand a phenomenon. The goal is understanding rather than explanation. Research does not seek to confirm a hypothesis, but rather to generate hypotheses on the basis of experience. Faithfulness to experience is a criterion of validity. Since 2010, we have been working within INSERM unit U669 as a specific research group (QUALIGRAMH) aiming to develop qualitative research projects in healthcare, and in adolescent psychiatry in particular. The goal of our research is to find more relevant resources for being attentive to the voices of adolescents within the context of complex pathologies, where both diagnoses and treatments require deeper understanding, on our part. At this conference, we would like to present three different projects, the approach to and results of which are important in the field of research centered on patient perspectives.

Adolescent obesity: results of a qualitative metasynthesis

Jonathan LACHAL, Child psychiatrist, AP-HP Cochin hospital, Maison de Solenn, Université Paris-Descartes, Sorbonne Paris-Cite, PSIGIAM, INSERM, Paris, France

Obesity is a major public health problem that is prevalent among adolescents. It has many psychological and physical complications. The family is the key to treatment, because nowadays, families are significantly involved in caring for patients. It is true that family relations play an important role in triggering and maintaining the disorder (1). Conventional models for treating obesity in the child and adolescent have failed, to a great degree (2). As a result, we are seeking to invent better models that understand the disorder. Because qualitative metasyntheses enable the principal players in the therapeutic relationship to speak out, they are essential tools in our research. We performed a metasynthesis (3) on 47 qualitative studies that questioned obese adolescents, their parents, or their therapists. Metasynthesis involves a third level of qualitative analysis, the first being that of the participants in the studies, and the second that of the researchers who published the studies (4). It makes a greater level of generalization possible (5). Our method of analysis is thematic, and based on phenomenology. We present our findings according to themes (6) belonging to three categories: "Seeing and being seen," "Understanding and being understood," and lastly, "Treating and being treated." The three agents in the treatment (the child, the parent, and the therapist) find it difficult to perceive and name obesity. It is as though the encounter between these three individuals never occurred. The absence of shared representations of obesity interferes with the construction and stability of the therapeutic relationship. A flow of representations within the child-parent-therapist triad ought to be a prerequisite to any therapeutic proposal for treating this situation. Listening to the experience with this illness of adolescents and their parents makes it possible to adapt treatment to their expectations.

A phenomenological approach to attempted suicide in adolescents and young adults: a qualitative study

Massimiliano ORRI, Psychologist, Maison de Solenn, INSERM, PSIGIAM, Paris, France

Understanding the perspective of adolescents involved in suicide attempts is vital to improving care and prevention. The goal of this research is to explore the subjective experience of adolescents who have made a suicide attempt (SA), and to describe how they give meaning to the act of committing suicide. Method: We conducted one-on-one interviews with sixteen participants (eight girls and eight boys). The interviews were made up of open-ended questions, in order to obtain a detailed description of their experience. The interviews were retranscribed and then subjected to a series of thematic analyses according to the Interpretative Phenomenological Analysis method. Findings: The subjective experience of adolescents who have attempted suicide is characterized by two axes of experience. The first axis represents the individual dimension of the suicide attempt; its two themes describe (1) negative emotions and the experience of being at a dead end, as an individual, and (2) an attempt to recover some control, by attempting suicide. The second axis describes the relational dimension of the suicide attempt; the three themes that belong to it are (1) the feeling of being at a relational dead end, (2) the suicide attempt as an effort to communicate with friends and family, and (3) revenge. Discussion: Our participants describe the experience of a dead end that is both individual and relational. The suicide attempt is experienced as a way out of this dead end, by arousing the other's concern for one's own individual suffering. Revenge is an important factor, because it constitutes the connection between the individual's own suffering and the other. Conclusion: The qualitative method made it possible to dedicate a space to expressing the suffering of adolescents who attempt suicide, by enabling them to express private feelings like revenge. It appears to be necessary to take these aspects into consideration when caring for these adolescents. References: 1. Smith J, Flower P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research. 2009. SAGE, London.

Photography as a medium for the patient's voice: an example of the use of photography in qualitative research with adolescents

Jordan SIBEONI, Child psychiatrist, AP-HP, Cochin hospital, Maison de Solenn, Paris-Descartes University, Sorbonne Paris-Cite, INSERM, PSIGIAM, Paris, France

Photography is not a recording of reality; it is an active, subjective creation of reality. We interpret a photograph using contextual, subjective, and intersubjective clues. In itself, the image carries no meaning: it does not speak for itself. It acquires a meaning only when it is given a caption. Photography produces more than an image; it also makes it possible to produce a text, a caption. The creation of a photograph also involves a reflexive process in the photographer, who might explain what he wanted to show or symbolize. He might write a caption for the photograph that expresses the meaning he confers on the picture, elaborating his theory as author. 1. The use of photography in research might therefore be integrated into a qualitative, phenomenological approach: the photograph and the discourse it prompts may succeed in bringing out the language of subjective experience, the subject's voice. In fact, a photograph taken by a participant may serve as a narrative medium for a research interview. This is photo elicitation. 2. We used this visual narrativity method drawn from anthropology for our work within the QUALIGRAMH research group on adolescent psychiatry. We carried out several qualitative studies that applied photo-elicitation, thereby exploring two questions: on the one hand, access to treatment for adolescents presenting depression, and on the other, the role of food in family relations among adolescents, some of whom presented disorders related to weight. We will show that the use of photography in these studies facilitated the verbalization of thoughts and emotions, improved participants' insight, and enabled them to give meaning to their subjective experience.

The voice of cancer patients near the end of life and its contribution to ethical analysis of decision making practice

Jan SCHILDMANN, Researcher in clinical ethics, Ruhr University Bochum, Institute for Medical Ethics and History of Medicine, Bochum, Germany

There is an increasing number of empirical studies on patients' perceptions and views with regards to treatment decision making near the end of life. An argument frequently forwarded in favor of such type of studies is that they make patients' voices heard in the clinical ethics debate. However, only few studies explicate their methodological premises and provide a more detailed account in which way the empirical data contribute to clinical ethics and more specifically can improve clinical ethics support services. In this paper we will present a concrete example of a qualitative interview study with pancreatic cancer patients, in which we explored patients' perceptions and preferences on information and treatment decision-making. We will present the rationale for the research, the qualitative method and selected findings from the research focusing on the different stages of decision making (i.e. trust based decision making versus information seeking) as well as the perceived difficulty of patients to anticipate the moment at which stopping cancer treatment would be the right decision. As part of the methodological reflection we will focus on epistemologically and normatively relevant premises of qualitative research methods and their relevance for the integration of normative and empirical analysis in empirical ethics research. For the purpose of our presentation we will restrict our methodological account on those empirical ethics studies which aim to provide guidance regarding ethically acceptable treatment decision. Based on our methodological analysis we will critically discuss whether and if yes under which premises this study contributes to make the patients' voices heard in the clinical ethics debate and may support the work of clinical ethics support services

The patient's voice and a qualitative research method in clinical ethics

Marta SPRANZI, PhD, Associate professor in history and philosophy of science, University of Versailles St-Quentin-en-Yvelines, Centre d'éthique clinique, Cochin Hospital AP-HP, Paris

The clinical ethics studies that we conduct at the center for clinical ethics are meant to unearth the values of all stakeholders in medical decisions, and more particularly, patients' values. In order to attain this objective we have developed a qualitative clinical research method which has two main characteristics. Firstly, it is « constructivist », insofar as it is founded on the idea that ethical arguments and concepts are not predefined but are constructed by the parties themselves during the interviews when they elaborate on their own experience. Secondly, we let arguments emerge, instead of checking whether they are present or not in the narrative. In this respect, the method used for gathering data is a form of « grounded theory » and the method used for analyzing date is based upon « sequential thematization ». Indeed, the relevant categories are constructed in a data-driven way : they emerge from reality rather than functioning as a tool of investigation and they are identified in an iterative way by comparing what emerges in a given situation to the next ones.

As to our positioning as researchers, we are aware of the fact that we are not mere « observers »; rather, we are what Stella Reiter-Theil calls « embedded researchers ». Even though we do not take a stand on the issues discussed during the interviews, the questions we ask do help our interlocutors to better understand his/her own position. Therefore, we might well indirectly influence the decision that will be finally made. From this point of view, even though our method gives equal voice to all parties concerned by the decision making process, the « patient's voice » can emerge in a special way. Patients are encountered individually and are interviewed in a non directive way for as long as it takes, sometimes repeatedly, so as to allow them to recount in a holistic way the biographical elements necessary to a fine comprehension of his/her ethical position. The main elements corresponding to the interview's keywords are sometimes recovered only a posteriori in the narrative. We may also limit our questioning during the interview if we have the impression that we are being too intrusive or doing some harm. Indeed, we are bounded by the fundamental ethical principle of « above all do not harm ». In the second part of our paper, we would like to discuss two main issues which we consider to be crucial. Firstly, can we preserve a form of objectivity in understanding the patient's story, given the subjective nature of the encounter and its emotional impact ? We would like to suggest a procedural answer to this question, based on our multidisciplinary approach. Secondly, is there a contradiction between the « do not harm » principle that we set for our investigations and the research goal ? We shall try to show that this is not the case. We shall refer to a few examples drawn from our empirical research studies.

ROOM 6: Who best gives voice to the interests of the (future) child?

Chair: **John D. LANTOS,** MD, Director Children's Mercy Bioethics Center, Kansas-City, USA

The child's voice in assisted procreation: Future parents, healthcare professionals, society; who knows best whether conception is desirable?

Sylvie EPELBOIN, MD, Department of reproductives technologies, Hôpitaux Universitaires Paris Nord Val de Seine AP-HP, Paris, France

Many cases referred for Medically-Assisted Procreation (MAP) are routine situations involving a problem with fertility within the couple. They raise no special questions about the future family. However, borderline cases that come up for discussion in MAP clinics involve reconciling the couple's request and the welfare of the child who will be born. The medical staff feels responsible for the child in a variety of situations that might compromise the future welfare of the child. A few of these backgrounds are: the age and deteriorating physical or mental health of one of the parents; limited life expectancy, very little material means and security; or a complexity of genitors, likely to compromise genealogical identification. The specificity of the ethical question in MAP resides in the fact that the technique requires a medical third-party who plays an active role in starting the pregnancy and interpreting society's thinking. This represents a fundamental departure from usual medical practice based on reacting to a situation presenting an established risk to the mother or child. The parents-to-be feel they are the sole authorities in determining the quality of life for the child they wish to conceive. They demand to make a decision autonomously; they say they are entitled to take advantage of the technology available. Nevertheless, plans to have a child and the request for MAP may be motivated in part by feelings that the procedure will avenge earlier mishaps: disease, a shorter life expectancy, the failure of a previous marriage, at the origin of wishing to bear a child late in life, or a situation of poverty or social exclusion. This bitterness tends to arouse the apprehension of the clinical team. Professionals have never reached consensus on the situations they suspect may be a risk for the child. However, a variety of implicit prevention attitudes prevail, depending on the values and experiences of each. These attitudes are not exempt from personal projections. They integrate presumptions about the child's future and the quality of his life, as well as society's current position in relation to such requests; its impact in terms of public health; and the staff's wish to protect itself from reprisals, should they refuse a request (they might be accused of abuse of medical power, discrimination, or endorsing eugenics). Conversely, they may also wish to avoid censure from other healthcare professionals, pediatricians, in particular, who might accuse them of failing to think through the effects of the procedure, or of a compassion-based approach associated with futility. To what degree should the physical or mental risks to the child outweigh consideration of the parents' physical or psychological suffering? What resources are available to answer these questions properly? These are the real questions, concealed by the hollowness of the expression of the child's welfare. We shall develop these questions by going into some case studies from clinical practice. In MAP, when many ethical principles may be in conflict, the one that dominates (autonomy, justice, beneficence / non maleficence) emerges on a case-by-case basis. The staff attributes varying amounts of attention to the couple's request and hope, versus projections regarding the life of the child to come. These are sources of concern, but there is little evidence for any of the knowledge we now have.

What weight should be given to parents' reasons in paediatric clinical ethics consultations?

Lynn GILLAM, Associate professor, Royal Children's Hospital, Melbourne, Australia

At the 2013 ICCEC, we presented the concept of the "Zone of Parental Discretion" as a tool for use in paediatric clinical ethics case consultations. We argued that in cases where parents disagree with doctors' recommendations, the first question in the ethics case consultation should be whether the parents' decision falls within the Zone of Parental Discretion, rather than what course of action is in the best interests of the child. We also argued that the reason for the parents' decision is not relevant: what matters is the effect on the child of parents' the decision. Our claim about parents' reason provoked considerable discussion, so in this paper we further explain that claim, demonstrate its implications, and argue further in support of it. Claiming that parents' reasons are irrelevant neither privileges nor discounts religious reasons for refusals of or demands for treatment: religious reasons get no special treatment either way. Similarly, it does not matter whether parents' decisions are based on disbelief in the medical explanation or irremediable misunderstanding; or whether the parents' motivations are good or not. Still the only thing that matters is the effect on the child. There is no sound basis for the clinical ethics committee or consultant to make judgments about the nature or worthiness of the parents' reasons. This may seems counter-intuitive, but the key is understanding the nuances of assessing the impact on the child of the parents' decisions. Using case examples, we will show how the impact on the child of the parents' decision is mediated by what the parents believe, in ways that can make that impact worse or better than it would first appear to be. We argue that this is the ethically most valid approach to dealing with conflict between parents and doctors in clinical ethics consultation.

Ethical and Practical Solutions to Engaging the Pediatric Patient's Voice

Rebecca GREENBERG, Bioethicist, The Hospital for Sick Children, Toronto, Canada

The patients' voice is not always given as much prominence in the health care of children as is given to health care professionals (HCPs) and substitute decision-makers (SDMs). This paper will explore the ethical issues in the pediatric setting that contribute to the minimization of the patients' voice and how clinical ethics support services (CESS) can assist in promoting the patients' voice. These challenges can be classified into two categories: 1) developing autonomy of the child, and 2) challenges arising with parents as SDMs. Firstly, the developing autonomy of the child can be an impediment to children's voices being adequately heard. The capacity of children to participate in health care decision making grows over time. Although not all children may be capable of providing consent or understanding all the issues involved in their health care, many have a keen interest in what happens to their bodies. In the province of Ontario, Canada there is no age of consent. HCPs presume a patient is capable regardless of their age, unless there are grounds to believe otherwise. Children who do not have capacity should still be included in decision making and informed about decisions that have been made for them to the extent they can understand and at an age appropriate level. Involving children in some aspect of decision making is empowering, encourages them to take an active role in their health care, recognizes their developing capacity to do so, and contributes to improved compliance and coping. Challenges also arise working with children who are chronically ill and involved with the health care system over an extended period of time. Although the capacity of children should be reassessed over time (in some jurisdictions i.e. Ontario), it is not uncommon for HCPs, out of habit, to continue to use parents and not involve children in their care in an incremental manner. Despite the ability to involve children, even if incapable, HCPs tend to bypass children and work exclusively with the parents. CESS can work to foster the patients' voice through the education of HCPs and parents about the importance of involving children in their care and the ramifications of discounting the child's voice, values and wishes. Secondly, in pediatrics the use of parents as SDMs is pervasive. When working with parents it can be challenging to ensure the patients' voice is central. This can occur as it is not uncommon for parents to want to protect and shield children from anything they construe as upsetting (e.g. a diagnosis or prognosis). As a result parents commonly request, and at times demand, withholding of information and/or providing deceitful information to children in an effort to protect them from hearing upsetting information. This can put HCPs in an ethical dilemma as they struggle with providing family-centred care and respecting the wishes of the parents, while also honoring the developing autonomy of the child. Common themes that contribute to this dilemma and how they can result in the minimization of the patients' voice will be discussed. They include: truth-telling, disclosure, confidentiality and privacy. The CESS works to mediate these dilemmas and support the involvement of the patients' voice and values. This presentation will highlight these ethical challenges and present innovative ethically grounded frameworks and strategies that have been embedded in Canadian law and policy.

The autistic child, his parents, and child psychiatrist: from polyphony to dissonance

Stéphanie PALAZZI, Child psychiatrist, 5e Secteur de Psychiatrie Infanto-Juvénile du Val-de-Marne, Boissy-St-Leger, Paris, France

The specificity of child psychiatry is that even though we are treating an individual patient, we have to listen to several voices: that of the patient, and also those of the parents. Our practice with children presenting autistic disorders has changed considerably in the past ten years. Patients' rights and easier access to medical information have obliged us to reconsider our relationship with parents, who now ask us for results as well as information. The alteration introduced in the choice of approaches to treatment is stimulating for us. It encourages us to be bolder, more open, and more disciplined. For example, we now assume the task of announcing a diagnosis of autism, just as our colleagues in somatic medicine have always assumed the task of announcing the diagnosis of an incurable disease. We accept the duty to defend our treatment choices, even if we sometimes have to yield, like it or not, to the parents' opinion; they are sometimes right and sometimes wrong. These new ways of working have generated a practice that respects an ethic of the patient, but also of the subject, whether he is a patient or a parent. Although there are not many situations that pose a problem for us, the ones that do are relatively similar in structure. They are characterized by a parental discourse that relies on two new principles: the rise in prominence of family associations as the primary interlocutor for guardianship, and the 2005 law that makes it possible for parents to sue for their child's right to special education at school. In such situations, the parents claim that special education at a public school is simultaneously an entitlement and sufficient care. Denying any idea that the treatment of a psychological disorder requires special training, parents maintain that they know better than anyone else, and, notably, better than any psychiatrist, what is good for their child. Confronted by these parents, we are soon trapped in a bind between the discourse on entitlement: the patient's right which, by extension, would be the right of the patient's parents, and what we believe is appropriate treatment for the child in our care. We must listen to what the parents of our patient are saying, and despite everything, continue to maintain that any child requires more than training and education: the child's development depends on the consideration of his emotional life. Moreover, these parents must agree to question the child's role in the family, in terms of the daily routine as well as in terms of how they imagine and fantasize their family life. We face the question of treatment ethics in the following terms: at a time when the mere aura of the psychiatrist's expertise is no longer enough to structure a program of treatment for a mental disorder, how can we assert a position which simultaneously acknowledges the relevance of the social discourse on the importance of education and training, and yet advocates the idea of an eminently singular approach to each patient, so that work on the subjectivation of the child can be done? We are reduced to a defensive position, trying to convince. For the sake of our patient, we must assume the burden of the parents' aggressiveness, ambivalence, or fear. Our efforts are meaningless unless, ultimately, the work of the child's subjectivation becomes possible. We are still wondering about these situations where, because we tried to walk on a tight wire, we quite simply fell off, with the bitter feeling that we have failed to make the voice of our young patient heard.

13h00-14h00 LUNCH - POSTERS SESSION (2)

Friday, April 25, 2014 afternoon

14h00-15h30 PARALLEL SESSION (4)

ROOM 1: Patients' values and religion

Chair: **Jacques QUINTIN,** Philosopher, Sherbrooke, Canada

Silos of Care: How Unit Cultures Shape End of Life Experiences for Patients and Families

Monica GERREK, Director of ethics program, associate researcher, Metro Heath medical center, Western University, Cleverland, USA

In response to widely documented racial and ethnic disparities in health, medical providers in the US are encouraged to exercise 'culturally competent care,' i.e. practicing in a way that is sensitive to the needs of patients from a wide range of racial, ethnic and cultural backgrounds. Although the push for cultural competency is certainly justified, there is little consensus in the social scientific and clinical literatures about what culture is and how it operates in clinical encounters (Lo and Stacey 2008). Given this lack of conceptual clarity, it is not surprising that, in practice, culture is operationalized as a set of beliefs and behaviors uniquely associated with patients. Rarely is culture understood as something healthcare providers and healthcare institutions also possess. This oversight in the conceptualization of culture has clear implications for achieving patient-centered care. Based on seven months of ethnographic observations in a 600-bed hospital in the Midwestern United States and 42 in-depth interviews with the families of patients who died in the hospital, we suggest that not only do patients have racial/ethnic, religious and cultural backgrounds that shape their interaction with providers, but that floors/units within hospitals also constitute cultural spaces that directly affect patient care. Looking specifically at end of life services, we argue that "unit cultures" (defined as the beliefs, practices and assumptions shared by a given unit or specialization in a hospital) profoundly influence how providers in various specialties think about death, how they view their role in end of life care, and what information they impart (or do not impart) to patients. Bringing their cultural viewpoint with them as they interact with patients across the hospital, providers come into contact with patients who have their own set of beliefs and orientations. We suggest that these interactional moments—where provider cultures and patient cultures meet—play a significant role in determining 1) what dying patients (and their families) understand about their impending deaths, 2) how patients and families make decisions about curative and palliative services and 3) how surviving families feel in the months and years after a loved one has passed away.

The Medically-Assisted Procreation elect: religious and secular values

Séverine MATHIEU, Sociologist, Lille 1 University, Paris, France

Some of the couples who resort to medically-assisted procreation (MAP) are religiously observant. When they approach a MAP clinic, they may want their religious values to be taken into account by the healthcare staff. A 2005 memorandum reasserted the principle of secularism in the hospital setting. This document bans proselytism, of course, but it also stipulates that "the healthcare facility must respect the beliefs and convictions of the individuals it serves. As much as possible, a patient must be permitted to follow the precepts of his religion." Nevertheless, it is essential "to ensure that the expression of religious convictions does not harm the quality of care and rules of hygiene." Healthcare staff members are subject to an obligation of "neutrality"; they must refrain from stating their religious convictions. Within the secular setting of the public hospitals, how can these religious values be understood? How are they understood? In part, this question motivated a sociological study of an ethnographic nature (we sat in on 150 visits and many staff meetings, and conducted in-depth interviews with patients and personnel) carried at a sperm bank and MAP clinic in 2009-2010. Although the patient-doctor interview involves several subjects, some of them quite intimate, they take place within a medical perspective – MAP – and, moreover, in a secular institution. Despite all of this, and even though the public-hospital staff is subject to the neutrality principle, the users are not. Users are careful to remain within the medical framework, but the secular space of the hospital may nevertheless be a place of compromise, confronted with requests that originate with religion. Does the theme of religion come up in the clinicians' daily practice? A review of our data on visits indicates that it appears only rarely. In great part, this is due to the fact that it would simply be inappropriate to discuss religion within the framework of a medical procedure. So many other matters must be said and discussed (test findings, protocol to follow, etc.). Moreover, MAP itself acts as a filter in relation to religion. Obviously, extremely devout individuals, who follow to the letter the norms regarding procreation decreed by their religious authorities, would never cross the threshold of a MAP clinic. Still, couples sometimes bring religious values to the attention of the healthcare staff (they may request insemination compatible with the religious calendar, for example). At that point, their requests may or may not be accommodated. MAP providers may also mention their patients' religious practices, in order to identify someone's reaction (for example, to understand why they refuse donor insemination). In this talk, I suggest we determine what is acceptable, when considerations of a religious nature are expressed by the patients, and the criteria that justify such a decision, in order to evaluate the basis for these possible divergences in values.

"I want a doctor who isn't Catholic.....!" Patients' values vs. health care workers' values

Kurt SCHMIDT, Clinical Ethics Consultant, Center for Medical Ethics, Frankfurt, Germany

Modern societies are characterized by a profound moral pluralism. Since there can be no "external" evaluation of what kind of treatment an individual patient in a specific situation would or would not like, the patient's voice is crucial. But does this make it part of the (new?) professionalism of health care workers to disregard completely all their own personal values and, for example, offer or inform patients "neutrally" about every option which is medically indicated, technically possible and legally permitted, even if their own values prevent them from condoning such measures? Specifically: May physicians refuse to perform certain interventions for religious reasons? May physicians refrain from informing patients about certain methods of treatment (e.g. the "morning after pill") for reasons of personal conscience? Is it part of their job description to curb the influence of parents making decisions for a child on the basis of their own values, ignoring the values of that child? On closer observation these questions are quite complex. On the one hand, the (religious) conscience of the physician is often emphasised as the crucial authority; on the other hand, it is precisely decisions made by physicians based on personal values which are revealed to be a possible source of discrimination: patients could be in danger of not benefiting fully from medical science. The following demand was made by Julian Savulescu in the British Medical Journal in 2006, for example: "If people are not prepared to offer legally permitted, efficient, and beneficial care to a patient because it conflicts with their values, they should not be doctors" (BMJ 332 (2006), p. 294). This contribution introduces a method which facilitates the preventive addressing, differential analysis and in-depth discussion of this complex issue. Its starting point is a sequence from a TV series set in a hospital, which through its drama impressively and intelligently highlights the significance of personal values in a situation involving parents, an adolescent patient and an interdisciplinary team of health care workers. It also reveals how hierarchies, gender, cultural mix and provoked emotions all play a role in such conflicts and makes it difficult for the patient's voice to be heard. The method explicated here is also well suited to teaching clinical ethics consultants how to proceed sensitively when an ethics consultation involves an (unspoken) accusation that health care workers are acting unprofessionally because they are allowing their own values to dictate the decisions they make.

"How Do You Know What I Mean?" Exploring the Limits of Autonomy: When the Patient's Voice Is Impeded or Ambiguous

Kurt SMIDT-JERNSTROM, Chaplain, Spiritual Care, Kaiser Sunnyside Medical Center, Clackamas, USA

The patient's voice is an expression of his or her autonomy, of his or her values, priorities, and intentions. The patient's autonomy is a crucial component of ethical medical decision making. Respect for the patient's autonomy is realized in the process of shared medical decision making between the patient and the physician. Ideally, the patient's voice is unambiguous, but when the patient's voice is occluded or distorted by pathological processes either physiological - such as a stroke - or psychiatric - such as depression, ethical problems can arise when the patient's preferences can not be determined or are contradictory, which in turn can lead to an impasse in the medical decision-making process. The ethics consultation process can facilitate medical decision making by reframing conflicting narratives that are based primarily on autonomy into a common narrative that is based on balancing autonomy with other principles such as beneficence, non maleficence, and justice, focusing on a benefit/burden analysis and then negotiating differences. This process is demonstrated in a case from practice which deals with a 68 year old man who suffered a series of strokes resulting in severe dysphagia, decreasing consciousness and occasional agitation. He lacks decision-making capacity and has an advance directive indicating full code and tube feeding if necessary. Because he pulls out his feeding tube and needs to be restrained, nurses working with him believe the treatment is against his wishes, and the physician believes the treatment is ineffective. The patient's family is conflicted - most wanting to honor the patient's advance directive, others believing that the patient would find current attempts at treatment undesirable.

ROOM 2: Using gamete donation: to what ends?

Chair: **Bertrand PULMAN,** Professor of Sociology, Paris, France

Public "social egg freezing" in Italy: women's desire or women's right?

Luciana CAENAZZO, Professor, Legal Medicine, Padua University, Padua, Italie

In this presentation we report some ethical considerations regarding the so called "social egg freezing": the cryopreservation of a woman's oocytes for non-medical purposes. Egg freezing for social reasons means freezing egg storing of a healthy, fertile woman, in order to have a pregnancy later in her life. The best-case scenario of elective freezing is when a woman in her late twenties or early thirties realizes that, although she has a strong desire to become a mother, she is unlikely to be in a good position to have children in the coming years for different reasons. She knows that by the time she will be ready to reproduce, her oocytes will have aged considerably or her ovarian reserve will be completely depleted so that she will remain childless. This woman could therefore ask for an alternative option, namely to cryopreserve the young oocytes she has today and use them to establish a pregnancy by In Vitro Fertilization and Embryo Transfer (IVFET) at a later point in her life. The Gynecology Department of Padua Hospital, recently have received some requests by women in order to obtain this medical service, and the management asked an ethical consultation. In the Padua hospital the oocyte cryopreservation is an accepted procedure to counter infertility for medical reason and in this case the treatment costs are covered by national healthcare system (totally or in co-payment). Egg donation for heterologous fertilization, in Italy, is not permitted. The ethical questions that are put in place are: - should the social freezing be provided in our hospital which is a public structure? Or is there a relevant distinction between "fertility preservation" focused on women whose fertility is endangered by diseases or medical treatments and egg freezing, used by healthy women as an 'insurance' against their age-related infertility? - From a medical point of view we have to consider the balance between the risks of the procedures (ovarian hyperstimulation and oocyte pick up) and the benefits, considering that the implantation potential of non-fertilized frozen oocyte and the "baby taken home " rate in this situation are not well known. - Should the Assisted Reproductive Technology (ART) founding be extended also for "social egg freezing" in the perspective of resources allocation for Public Healthcare System? The authors propose the ethical argumentation given by the counselors in our case, deepening pros and cons for "social egg freezing" considering the Italian public hospital reality and the Italian law on ART. In fact elective oocyte freezing consists of two separate steps that are clearly distinct in time: first, ovarian stimulation, oocyte retrieval, cryopreservation and storage and second (several years later), thawing and fertilization of the cryopreserved oocytes. At the time of the first step, women who request social freezing are healthy persons who ask for a procedure that results in stored oocytes that may or may not be used, depending on the further course of their lives.

In favor of non-anonymous embryo donation

Emilie GUERIN, a patient, Amiens, France

Testimony: "Having confronted the experience of infertility ourselves, today we would like to donate embryos to help other infertile couples. However, the law does not permit us to do so under the conditions we require. We are pleading for an amendment to the legislation to lift donor anonymity should the donor request. We had a difficult Medically-Assisted Procreation (MAP) process that lasted for four years. Then, in April 2009, we were lucky to obtain three embryos by IVF. We were delighted when the first transfer enabled us to have a little girl in December 2009. The other two embryos were cryogenically preserved. Then, we had a second child "naturally," a son born in July 2012. Every year since the IVF, the hospital has asked us what we intend to do with our frozen embryos. We are given four options: to continue the cryogenic preservation, to donate them to a couple, to donate them for medical research, or permission to end their preservation. This year, after the birth of our son, we do not plan to have a third child for the moment. We decided to donate our embryos to an infertile couple. However, the IVF lab informed us that, according to law, if one or more children are born as a result of this donation, they will not have the right to know who their genetic parents were, if they seek that information. We thought about it, and unhappily decided not to make the donation. We refuse to agree to a donation if the children that may be born as a result might someday feel lost and miserable, denied the right to know their "whole story." More than anything, we would like to be able to help infertile couples to make their dream of a child come true. Nevertheless, we find it unbearable to feel "co-responsible" for any grief that might befall a child, if he wants someday to have access to this knowledge about himself. We have also thought about the impactthat sharing this "medical and genetic truth" with a young adult might have on our own lives some day. We are fully ready to assume it. We are convinced that it is wrong to keep facts about genetic parents secret from the people seeking that information!

Patients' voice and procreative tourism for gamete donation procedures: an impeded voice?

Vassiliki SIMOGLOU, Psychology Researcher, Assistant Lecturer, Paris-Diderot Paris 7 University, Paris, France

Couples struggling with infertility and being oriented towards gamete donation, sooner or later find themselves crossing the borders of their own country in order to address their demand abroad. The subsequent boom of gamete donation procreative tourism can give rise to a multitude of misuses on both subjective and collective levels, among which I underline explicit and implicit body co modification. Faced with the discrepancies in the legal context of application of Assisted Reproductive Technologies (ART) among different European countries, the particularities of the Greek and French paradigms will be put into perspective, and the principles of gratuity and voluntariness will be considered. The cross-border patients' ambivalence, insecurity and hope, such that they are expressed during the clinical interviews, thus become a vector of their impeded voice as citizens. Conveying feelings of rejection and loss in their own country, urgency and omnipotence in the hosting country, they seem to be captured in the medical fantasy of responding to patient requests at face value. Therefore, fostering the patients' impeded voice invites for a reevaluation of our capacity to embrace patient demand and implement personalized therapeutic processes. It also calls upon our ethical stance not only as healthcare providers, but also as citizens implicated in societal change. Social and unconscious aspects of gamete donation filtering the patients' voice, lead to a questioning on the existence of specific gamete donation 'politics' in the countries where it is practiced. Would there donor recruitment 'politics' exist, specific to a country's customs, history and culture? How will a country's 'politics' manage donor shortage, resulting in the lack of self-sufficiency and inability to support a population that becomes more and more demanding? How, in another country, will it regulate recurrent gamete donations, rendering donation a professional occupation or even the potential abuses of forced donations, such another type of human trafficking? European global (?) 'politics' would it be able to standardize practices in order to minimize the risks and protect donors, recipient couples and children born this way?

The use of the Freudian "family novel" in structuring a father and mother, within the framework of counseling prior to sperm donation

Claire SQUIRES, Perinatal Associate Professor, Child Psychopathology, Paris-Diderot Paris 7 University, Paris, France

Couples embarking on an IVF procedure with donated sperm are always offered at least one session of psychological counseling, and they may engage in a series of sessions. This counseling enables the couple to grasp the experience and meaning of the procedure. It is also an opportunity for them to project themselves into their future as a family, to structure themselves as the father and mother of the child who will be born. During this special moment, which ranges from questions that are left unspoken and painful admissions, ambivalence prevails over the articulation of what will enable them to cope with the ordeal of infertility. In the course of these emotionally-charged sessions, the counselor can identify an explicit, uttered language, and an implicit, underlying language. The phenomenon tests the counselor's ability to hear a half-spoken truth and bring it into the open as a full-fledged statement. Patients' voices change. In the beginning, they are often loud and animated; they become softer, hesitant, and barely audible. As the defense mechanisms loosen, the couples open up to the third party willing to listen to them. At that point, one watches as they struggle with the impossibility of elaborating their wish for a child, a wish that is immobilized by overwhelming emotion. These feelings are always connected to the vicissitudes of the individual's own "family novel." At times, the individual may sob at the mention of the death of his or her own parents, when either partner is trapped in grief that appears interminable. Bearing the burden of transmission, the medical procedures are a door to renegotiating the place of each in the transgenerational bond. In such a case, the sessions are impregnated by these mental rearrangements. The counseling session opens a breach, and out flow family secrets, stories of surgery undergone in infancy, fears that mental illness may run in the family, and individual stories of traumatic abandonment. Everything that seemed to have been put away for good comes out, and is endowed with meaning. In the case of a sterile man, the possibility of procreation with sperm from a third-party donor must be invested with meaning. He must structure himself as the father of the child, bearing a mark, but distinct from his own father. The future parents and the counselor realize that the pregnancy to come will be a time of recovery and healing; the couple will share the woman's experience of carrying the child during the gestation. The man's presence throughout the pregnancy enables him to project himself into the paternal role in relation to the child. In conclusion, in order to permit the couple to structure their attitude towards the medical procedures, the clinician must be capable of great attention to the patients' voices, making a special effort to hear what is said and what is uttered.

ROOM 3: The Voice of the Elderly in Nursing Homes

Chair: **Reidun FORDE,** MD, Medical Ethics Professor, Oslo, Norway

Coping with the silence of institutionalized elderly people

Nicolas FOUREUR, MD, Centre d'éthique clinique, Cochin Hospital, AP-HP, Paris, France

For several years, the Centre d'Ethique Clinique (CEC) at Hôpital Cochin (AP-HP, France) has taken an interest in the ethical questions raised by medical decisions in geriatrics, both at home and in assisted-living hospitals or facilities. It has carried out several studies on people over the age of 70 regarding treatment for colon cancer, cardiological care, the concept of advance directives, and life in an institution for the elderly. The "silent curtain": Gradually, a disturbing, prevailing phenomenon came to light. "The elderly" seem to become mute once they are institutionalized. It is as if they withdrew, and agreed to let other people speak for them, or make decisions for them; as if, once they were admitted to an institution, they accepted a lesser autonomy. Institutionalized by others, somewhat against their own will, they seemed to give up defending themselves entirely, physically and vocally. In any case, their autonomy is no longer valued. Institutionalization seems to represent a tipping point for their lives. The values of beneficence, of non-maleficence, and the question of safety overpower the question of autonomy. Patient autonomy is weakened to the point where organizational, administrative, and even corporatist priorities are imposed, at the expense of the individual's life story and values. The burden of beneficence: What do we observe? In the complicated network of values that emerges, caregivers often cite the best interest of the patient to defend their actions. However, the definition of "best interest" is debatable. In part, this is due to the subject's difficulty in expressing himself, speaking out, making his choices explicit. But it is also debatable because medicine is potentially less effective, for patients who are very old and dependent. The more their care is medicalized, the greater the risk of dehumanization and maltreatment. Often, medicalization is revealed as an easy, immediate response covering up other needs that have to go unmet. More generally, we felt that the more autonomy withdrew, the more it was replaced by beneficence. We believe that autonomy's voice should be restored. Paradoxical as it may seem, when the patient is withdrawn to this degree, individual autonomy must be the main guideline in the choices made for that person. It is the only counterweight possible. But how can we define autonomy, in terms of a very elderly person who often requires physical and psychological assistance? How can autonomy be understood? Should we listen to the little that the person says, at a time when that person's competence is questioned? Should we rely on all that clues that make an individual authentic and unique, on the basis of what that person says and how that person lived? To what degree should the person's family be involved in understanding the person's autonomy better? What if the interpretations are conflicting? These questions were the subject of a cycle of seven debates open to the public, on the relationship between aging, healthcare, medicine, and autonomy, organized by the CEC in 2011-2012. We had trouble bringing out the voice of these elderly subjects, even within the framework of a debate dedicated to that purpose. What can we conclude? The presentation, based on case studies, will be made by a doctor and a non-doctor, both of whom have worked on issues related to aging.

Elder Abuse in the U.S.: When the Family Mutes the Voice of the Patient

Shelley KOBUCK, PhD Student, Healthcare Ethics, Duquesne University, Pittsburgh, Pennsylvania, USA

The topic of elder abuse in the United States is one that creates great emotion and is typically associated with long term health care institutions and services such as nursing homes, assisted living facilities, and professional home health care workers. What doesn't receive as much focus is the prevalence of elder abuse from the patient's very own family members. Because of the reticence for the elderly to report such abuses it is difficult to capture the true pervasiveness but in a study reported by the National Center for Elder Abuse (2011) it was estimated that between 7.6% and 10% of the elderly people studied were victims of some form of elder abuse primarily from someone within their own family. The notion that family members are predisposed to care and caring attributes simply due to the genetic or legal relationship designation is a flawed one. When elder abuse occurs from the family, the voice of the patient is muted. The patient's wishes are no longer given preference and the best interests of the patient are no longer honored. This presentation will look beyond patient rights and utilize an ethics of care approach to support patient autonomy in family elder abuse within the U. S. welfare and legal systems. Elder abuse will be defined by the varying types of actions or inactions that fall within the parameters for abuse along with the facts and figures to show the occurrences. Patient rights and the legal guidelines for decision-making on the part of the patient will be discussed as it relates to setting a foundation for potential exploitation. An ethics of care will be analyzed as a virtue in care and caring with a comparison to the rights and justice approaches that currently exist. Lastly, a summary of proposals for prevention, identification, and protections for the elderly will be covered.

Patients and relative´s experiences of life and living in nursing homes

Lillian LILLEMOEN, Clinical Ethics Researcher, Centre for Medical Ethics, Oslo University, Oslo, Norway

Aim To find out how patients and relatives experience life and living in Norwegian nursing homes. Introduction The population living in Norwegian nursing homes has multiple and severe diseases and live an average of two years after admittance. About 43 % of all deaths in Norway occur in nursing homes. Presently resources, including enough staff with adequate training, do not meet the complex needs of these. Accordingly, nursing home personnel report that they frequently face ethical dilemmas caused by inadequate medical treatment, nursing care, and lack of resources to meet the psychosocial needs of the patients. Other ethical dilemmas reported are related to the patients' reduced decision-making capacity and how to respect the patients' autonomy. In 2007, the Norwegian Parliament voted to increase health care personnel's ability to cope with ethical dilemmas. The present study is part of this project; to gain increased knowledge of nursing home patients and their relative's views on ethical challenges related to nursing home treatment and care. Method The data is from a qualitative study of patients and relatives in six nursing homes in four municipalities in Norway: Seven group interviews with a total of 60 relatives of non-competent patients in nursing homes, and 38 individual interviews with competent nursing home patients. A qualitative content analysis of the interviews was conducted. Results Over all, patients and relatives report positive experiences and that their basic needs are met. Many positive characteristics are given related to life and living in the nursing home as well as their relationship with the staff: Delicious food, good care (always someone looking after you), activities and socializing. Both patients and relatives see the nursing home as a safe place to stay. Relatives acknowledge that their positive attitudes may be related to the fact that they initially had low expectations of life in a nursing home. However, many patients expressed that living in the nursing home was not a preferred situation. It is accepted as a necessity because impaired health made it impossible to stay in their own home. It is this situation which makes them sad, not the nursing home or the staff. Lack of diverse activities and insufficient stimulation for residents is primarily how relatives characterize the nursing home life. A minority of the patients and relatives have, however, more serious descriptions of loss of dignity, caused by disease or offenses by the staff: Verbal and physical abuse as well as negligence of the patient's individuality. These patients are discouraged and grieve the loss of their former lives. In general, relatives have mixed feelings about the situation: The institution relieves them from the heavy responsibility for their loved ones and thus gives them a sense of peace of mind, while at the same time they feel guilt and grief when they see that the person gradually changes and often becomes unfamiliar to them when losing his/her personality. Conclusion How patients and relatives experience life and living in nursing homes varies. A large group describes it in positive terms. To many the situation is acceptable because they see it as necessary. Powerful descriptions of the loss of dignity are given by a minority. These patients use the word prison about their life. Relatives describe how undignified it feels to see a mother change into a screaming person, unrecognizable to them.

Dementia, Sexual Autonomy, and Gatekeeper Responsibilities

Elizabeth VICTOR, Philosopher, Professor, Grand Valley State University, Grand Rapids, USA

We shed light on some of the conceptual and practical complexities associated with enabling the sexual autonomy of individuals with dementia. We focus on those who are in a daily position of dependence in assisted living facilities. Scholars and practitioners have called for fuller discussion about sexuality in the cognitively disabled for more than twenty years. It is morally urgent for clinical ethicists, caregivers, and policy-makers to consider how to accommodate the sexual interests of this population, irrespective of reproductive interests. Caregivers act as gatekeepers in deciding which options are available and acceptable for these individuals. As such, dementia residents are susceptible to barriers and vulnerabilities associated with the most intimate aspects of their lives. Given the import that sexual activity has for many individuals' sense of self, desire satisfaction, and interpersonal connections, the presence or absence of accommodation on this front can significantly affect residents' quality of life. This issue is further complicated because the diagnosis of dementia can lead to questions about capacity and trigger uncertainty among caregivers in relation to their obligations when residents express sexual preferences. There has been much ink spilled in bioethical literature on how best to respect and protect individuals with diminished capacity when major medical decisions need to be made. There has been significantly less attention on how to evaluate individuals' capacities for more routine decisions, such as those related to sexual activity. We argue that capacity determinations need to take into account the long-ranging harms that can result from the continual denial of sexual autonomy. A holistic picture of well-being and a relational view of autonomy can help prevent over-idealizations of what human beings need for the promotion of agency. Especially when someone faces changes to her mentation and living environment, additional limitations or stigmas on lifestyle choices can imperil what remains of the resident's narrative self-conception. However, given concerns about the vulnerabilities of this population, caregivers' responsibilities will be intricate and contextual. We contend that caregivers' obligations are positive as well as negative, and policies should provide supports and mechanisms for different forms of sexual expression. We suggest ways in which institutional provisions can ameliorate worries about residents' vulnerabilities without leading to the extreme and unjust conclusion that all non-ideal agents should be prevented from pursuing sexual lifestyles. Finally, we discuss broader institutional implications of our arguments. Specifically, we discuss person-centered care in clinical contexts and advance care planning through careful baseline determinations and the advantages of employing ethics services. Clinical ethics support services can alleviate moral distress, form responsible policies and systems, keep track of exclusionary practices, and advocate for the residents' short-term and long-term interests. Clinical ethicists are well-positioned to develop the skills necessary for tackling some of the core tensions and puzzles associated with discerning the true voice of an individual in different stages of dementia, and they play a key role in the continuing moral education of caregivers.

ROOM 4: Proxies and families in clinical ethics

Chair: **Silviya ALEKSANDROVA-YANKULOVSKA,** MD, Associate professor of Bioethics, Medical University of Pleven, Pleven, Bulgaria

End of Life Decisions for People with Significant Intellectual Disabilities

Marisa BROWN, Project Director/Research Instructor, Nursing, Georgetown University, Washington, USA

Our study analyzes and evaluates how guardians make end-of-life decisions for individuals with profound intellectual disability (PID) who have never had decisional capacity. This project explores two unique features of the moral problems associated with these decisions. The first is the complexity in identifying the best interests of the ward when, due to the PID, he or she has never had the ability to describe his/her wishes. In these instances, family members, lawyers, or other social service professionals are given the status of guardian and may be vested in making decisions that can either hasten or prolong the end-of-life process. We discuss some common questions and concerns associated with this "gold standard" of surrogate decision-making when applied to these individuals. For example, there are worries about surrogates completely de-personalizing the best interest standard, not making a concerted effort to determine the ward's preferences (to the extent they might exist), or simply deferring to medical judgment without critical reflection. Further, disability advocates express concerns about healthcare professionals and surrogates not being sensitive to the subtle ways in which wards with PID could communicate. The second unique feature to be explored is developing an understanding of how these decisions are made and should be made within a patient-centered framework. In response to these challenges, we have surveyed local guardians about their experiences making end-of-life decisions for this population, and we solicited their thoughtful responses to case vignettes. This research was done with assistance from scholars, lawyers, and disability advocates. Additionally, we have constructed a web-based toolkit to assist guardians tasked with making decisions for wards with PID. In creating this resource, we incorporated insights from our advisory committee and from aspiring legal professionals. Based on this input and our research, we determined what would be most helpful to guardians who are making these decisions. The toolkit includes frequently asked questions (and answers), ethics work-up guidance, case studies, literature review, case law overview, a guided interview for surrogates, a glossary of key terms and concepts, and a worksheet for discerning which conditions might be worse than death. Our toolkit highlights the ways in which guardians can take advantage of clinical ethics support services, including ethics committees. For those involved in clinical ethics consultation, our research and toolkit have utility as well, since we address some of the core sources of moral distress when making end-of-life decisions for individuals with PID. Our presentation offers innovative research, concrete recommendations, and a nuanced perspective on the complexities of giving proper voice to the particular needs and interests of patients with PID in times of crisis and intense vulnerability.

The voice of the patient and the interests of the patients' relatives

Ralf J. JOX, Assistant Professor on Medical Ethics, Institute of Ethics, History and Theory of Medicine, University of Munich, Munich, Germany

It is a cornerstone of patient-centered medicine that the treatment of patients has to be justified by its conduciveness to the patient's wellbeing and by his or her informed consent. Treatment that is not in the interest of the patient is usually regarded to be futile and thus not justified. There are some specific interventions that may not entail a benefit to the patient from an objective point of view, but the fact that patients want it or voluntarily consent to it at least suggests that they may associate it with some form of benefit from a subjective perspective. Examples for such interventions are participation in non-beneficial research or living-organ donation (usually for close relatives in need of an organ). Treatment, however, that is performed with the sole purpose and consequence to benefit relatives without the patient's consent is usually regarded as not being justified. Yet, there is abundant empirical evidence that such treatment is frequently being performed, especially if the patients themselves are incapable to give their consent. Life-sustaining treatment on intensive care units is sometimes continued only to reduce the anxiety of relatives. Artificial nutrition and hydration may be administered during the dying process although it may harm the patient, just because it apparently eases the relatives' fears and concerns. These situations often give rise to ethical case consultations in hospitals and nursing homes. In this presentation I will analyze whether and under which circumstances it may be ethically permissible to perform treatment that is only in the (presumed) interest of relatives, without having the informed consent of the patient. I will first show that the purely utilitarian and impartial view that would give equal weight to the benefit for patients and relatives is not sustainable in the medical context. The health care professionals' special obligation towards the patient not only results from the size of benefit, but also from the gravity of the patient's health care needs. In addition, purely instrumentalizing the patient for the sake of a relative contradicts the Kantian categorical imperative. Such treatment could only be ethically justifiable if three conditions are met: 1) the patient's presumed consent to the non-beneficial treatment can be reliably demonstrated, 2) the benefit for the relative must be significant and probable, and 3) the relationship between the relative and the patient must be close so that the wellbeing of both partly depend on each other. I will use different paradigm cases to illustrate this position and show how it can be applied to clinical decision making.

When Surrogate Decision Makers and Advance Directives Conflict: Finding the Patient's Authentic Voice

Hannah LIPMAN, Associate Director Montefiore-Einstein Center for Bioethics, Chief of the Bioethics Consultation Service, Associate Professor of Clinical Medicine, Divisions of Geriatrics and Cardiology, Bronx, NY, USA

When the surrogate decision maker for a patient without capacity chooses a plan of care in conflict with the patient's advance directive, bioethics consultation is often called upon to help determine which represents the patient's authentic values. The author, an experienced bioethics consultant, will use cases to present a process-oriented approach to resolving conflicts between the patient's advance directives and the real time decisions of surrogates. The impact of local laws governing surrogate decisions will also be discussed. The tools of medicine should be used to further the patient's goals. Patients who lack decision-making capacity may be unable to partner with clinicians to ensure that the plan of care reflects their values. Advance directives aim to give the incapacitated patient a voice. The proxy directive designates a surrogate decision maker. The treatment directive delineates specific types of treatments preferred in a given situation. Patients may have both a treatment directive and a proxy directive. Local law establishes a hierarchy of surrogate decision makers and the scope of their authority. When the surrogate's opinion differs from the patient's previously stated preference as detailed in a treatment directive, it is often unclear which more accurately represents the patient's values. Two main factors complicate the process of finding the patient's authentic voice. First, treatment directives are difficult to interpret. While on its face, the written treatment directive may appear to delineate exact patient preferences which must be adhered to, elucidating the meaning of a treatment directive is rarely so clear cut. A treatment directive is an "if, then" statement. It may be difficult to determine whether the "if" conditions are met. Written treatment directives often use boilerplate, standard language, which may inaccurately represent or omit important treatment preferences. Patients may not have anticipated the current clinical situation and/or preferences may have changed over time. The document speaks from the past to the present, but it is one-way communication. Clinicians cannot have a dialogue with the document to understand how the preferences the patient held at the time of its execution should be applied to the situation at hand. Second, surrogate decision makers are under stress. Surrogates are expected to minimize their own values, preferences, and concerns, but this is unrealistic. Surrogates are often those closest to the patient, love the patient and grieve that the patient is ill. Also important is whether the surrogate is the agent designated by the patient. There is no absolute rule that either the advance directive or surrogate decision maker should prevail. A process aimed at conflict resolution is useful to uncover the patient's authentic values. This includes: filling out the patient's story by interviewing him/her (incapacitated patients may be able to share relevant information about themselves), obtaining collateral information from other sources such as prior providers and others in the patient's community or religious networks, understanding the relationship between the patient and the surrogate decision maker, attending to the emotional distress of the surrogate(s), clarifying the patient's prognosis to determine if the "if" conditions of the treatment directive are met, and obtaining information about the circumstances surrounding the execution of the treatment directive.

Discovering ethical challenges with the involvement of relatives of geriatric patients. A case series

Laura ROSENBERG, Graduate Student on Medicine, Clinical Ethics, University Hospital Basel, Basel, Switzerland

Background In geriatrics it is often difficult to determine the patients' wishes, when they cannot make their voices heard due to impaired decisional competence (DC). Then, their relatives might help express the patient's will. This study explores how families of geriatric patients are being involved in the planning of treatment. Research questions: to shed light on ethical difficulties arising in this process and on what the concepts of patient autonomy and DC add to grasping the topic. An important new aspect was added to the subject of respecting the "patients' voices" in Switzerland with the new Civil Rights Law ('Erwachsenenschutzrecht') enacted 1.1.2013, strengthening both patient rights and the weight of surrogate decision-making by relatives. We will reflect the impact of this legal reform, exploring its challenges for healthcare professionals, patients and notably relatives, whose roles seem to undergo a considerable change: relatives risk being overcharged by a task triggering existential questions at the end of life. Method Three cases were documented using a structured form which was developed specifically for this purpose. All information was obtained using the „embedded researcher"(ER)-approach and semi-structured interviews with patients, relatives and medical staff. The ER is an independent observer on the ward and can access all information needed, without actively participating in the patient's care. Selection criteria: available family, important treatment decisions to be made, various degrees of patient DC. Results Major challenges in including relatives into treatment planning: Providing clear and sufficient information, dealing with disagreements between parties, managing compromised DC and substitute decision-making. Case 1 combines issues with disagreement, DC and substitute decision making, as there is dissent between staff and highly involved relatives regarding the therapeutic target as well as the patient's DC. In case 2 the main problem is disagreement between patient and doctors with the patient's daughter caught in the middle, being overwhelmed by the communication with care staff. The key issue in case 3 is an accident in communication between daughter and doctors and how it was handled. Successful exchange of information within the care team seems to be difficult to accomplish in the clinical setting. Therefore, the hot spots discovered in the documented cases were integrated in a structured form to help gather and organize the most vital information on the patient's will, his or her degree of DC, the relatives and the decision-making process. Discussion The study is not statistically representative. It might, however, through the detailed observations made by the ER provide valuable insight into decision-making processes and the involvement of the family in patients with various degrees of DC. The documented cases locate specific problems similar to those described in literature. Further, observation revealed that communication within the care team needs more attention. Thus, a form was developed to gather and organize important information about a case. It is hoped that the new documentation tool for the ward is practicable and helps identify situations where ethics support should be used. Moreover, it is expected to help revealing where the patient's will is particularly at risk of being overheard. Future research should focus on putting this to the test.

Ethical challenges related to next of kin in nursing care -a qualitative study

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Patients in clinical settings are not lonely Islands; they have relatives who play a more or less active role in their lives. The purpose of this paper is to illuminate ethical challenges nurses encounter in everyday nursing practice with patients' next of kin. The study is based on data collected from group discussions among staff from two clinical settings, home care for adults with learning disabilities and rehabilitation/ short term care. The discussions took place in 2011 and 2012. Data were analyzed and interpreted according to hermeneutic methodology. The next of kin to the patients were found to be an ethical issue frequently discussed in the groups. Findings indicate that next of kin had different characteristics interpreted as shadows, distant but powerful and professional. In the presentation we will describe the next of kin's characteristics and the ethical challenges nurses experience in this connection. We will place findings in an ethical framework of sensitivity and caring, we will discuss implications for practice, and we will focus on interventions to help nurses manage ethical challenges related to next of kin.

ROOM 5: Healthcare professionals strategies for coping with ethical challenges

Chair: **Pierre BOITTE,** Medical Ethics Professor, Catholic University, Lille, France

In search of good care; connectedness as a prerequisite to properly assess patient's voice in nursing decision-making

Ria DEN HERTOG-VOORTMAN, Lecturer/Researcher in Nursing Ethics, Christian University of Applied Sciences, Ede, Netherland

Wellbeing of patients in acute care is largely situated in the hands of the nurses who understand how to tailor individual nursing care in this stressed situation. In the paradigm of the Evidence-Based Practice, nursing decision-making moves between scientific research, professional knowledge and patient preferences to provide good care. The implementation of evidence from research attracted much attention in the literature; less is published about the use of professional knowledge or tuning in to the patient's voice. The aim of this study was to discover how nurses in acute care take patient preferences into account in daily nursing decision-making to provide good nursing care in the Evidence-Based Practice. This Grounded Theory study was conducted in the Netherlands and examines the experiences of 27 nurses (of whom 2 men), known as providers of good care. Data were collected through semi-structured interviews with attention to the narratives of the nurses. Nurses take the patient's voice into account in an active interplay of being attentive and influencing patient's responsiveness by monitoring patient's feelings of security and trust. They use 'click techniques' to create connectedness and take time to recognize the other as a special person. With their 'antennae' they assess the constantly varying patient preferences in sometimes rapidly changing circumstances. Patients themselves, their family and the caring team are the best reference frame to check nurses' impressions on wellbeing of the patient. Nurses themselves are hardly aware of their behavior to create connectedness. The intensive process of continuously assessing patient preferences seems to be a part of hidden professionalism and a prerequisite in providing good, individual tailored care. More research is needed to discover how nurses give weigh to the patient's voice in the nursing decision-making process and how forms of consultation can support them in this important search to individual tailored care.

Longing for an in-depth dialogue in hemodialysis care: Registered nurses narratives about situations evoking a troubled conscience

Catarina FISCHER GRONLUND, PhD Student, Department of Nursing, Umeå University, Tavelsjö, Sweden

Registered nurses (RNs) and physicians in dialysis care often have a long-term ongoing, relationship with their patients. Since they meet the patient under different circumstances the RNs and physicians often have different perspectives on the patient's situation. The point of departure for this study was that the head of a nephrological clinic asked an ethics committee for help concerning difficulties the staff had discussing ethical issues. Two studies were outlined; one focused on physicians who narrated that they felt torn, irresolute and burdened by having sole responsibility, by being questioned and criticized by the RNs for the decisions they made in ethically difficult situations. In this study the RNs in the same clinic were interviewed. Asking them to narrate any ethically difficult situation that evoked a troubled conscience may shed light on what RNs experience as ethical problems and open the possibility for further reflection. The aim of the study was to illuminate RNs' experiences of being in ethically difficult situations in dialysis care troubled their consciences. Narrative interviews with ten RNs working in dialysis care in northern Sweden were audio recorded, transcribed and analyzed using a phenomenological hermeneutic method. The analysis resulted in one theme, Longing for a deliberative dialogue, and six subthemes: Dealing with the patients' ambiguity; Responding to the patient's reluctance; Acting against the patient's will; Acting against one's moral convictions; Lacking involvement with patients and their relatives; and Being trapped in feelings of guilt. The RNs longed to have a deliberative dialogue because sometimes they had to act against their consciences and felt inadequate as they experienced that they had failed both the patient and themselves. They wanted to deliberate and exchange experiences with physicians, colleagues, patients and relatives in order to understand the patients' expressions and the whole situation. The text is interpreted in the light of the philosophies of Lögstrup, Fromm and Ricoeur concerning ethics and conscience. It involves that RNs in difficult, complicated and ethically ambiguous situations feel uncertain about what is the right and good thing to do. Failing to do good for the patient evokes a troubled conscience which leads to feelings of guilt. The RNs feel powerless and alone with their guilty feelings and want to discuss matters with the physicians and their colleagues. Failing to enter into a dialogue they cope with their guilty feelings by getting together in closed, like-minded groups to confirm each other by blaming those outside the group but they remain powerless and unable to work for change. Our interpretation indicates the importance of openness among all those involved in an ethical dilemma. By deliberating and being open to various aspects of the situation physicians and RNs may be able use their power together to judge and act in a constructive manner to achieve the best solution. Conclusion: This study indicates the importance of creating an open ethical climate where various healthcare professionals dare to give expression to their experiences regarding value conflicts and help each other to understand what might be the best, or the least bad, thing to do, in order to act in accordance with their consciences.

Transferring moral insights from moral case deliberations to other situations: the development of a moral compass

Laura HARTMAN, Medical Ethics PhD Student, Department of Medical Humanities, Amsterdam, Netherland

Moral case deliberations (MCD) are reflective dialogues on concrete cases and the underlying values and norms by health care practitioners themselves. Although participants are very positive about MCD as ethical support, MCD focuses mainly on what participants think about that specific case on that moment. Furthermore, MCD is relatively time-consuming (sessions take about 2 hours); and allows for only a limited number of people to join, learn and profit (about 10-15 per session). This warrants research into how these outcomes can be captured and transferred to other situations and other health care practitioners who did not participate in the MCD. Research questions and aims This research aims to investigate how and what kind of instruments can be developed, complementary to these series of MCD's. How can we capture and transfer the result and outcome of MCD into a more abstract instrument that offers moral guidance at other moments and for other health care practitioners? Reflections MCD is process oriented (dynamic) and yields a specific kind of knowledge. The outcome of a MCD is contextual knowledge about what is good in a specific situation. We cannot just generalize the outcome of a MCD of that case to other cases and other practitioners, since the contextual factors may be relevant. Still, how can these outcomes be made useful in a broader, more general context? Also, within the method of MCD, knowledge from guidelines or science cannot always be taken into account sufficiently. How to combine these different types of knowledge in a way that supports moral learning and gives support in facing ethical dilemma's faced by practitioners in healthcare on the work floor? In this presentation, we will reflect upon some theoretical and methodological questions that arise when transferring MCD insights into an instrument that can be used beyond the MCD context. We describe several theoretical insights that reframe ethics as a social activity. Professionals use their own vocabulary and reflect together about which points they consider important in a specific case. In this process the practical knowledge and implicit moral routines of professionals are discussed and thereby come into focus. This theoretical framework for ethics also changes the way we are able to transfer these ethical insights to a third party; ethics ceases to be a created subject to be transferred to practitioners, but a subject to be created by practitioners themselves. Case study I will illustrate these points by introducing a case study in which we have accounted for the reflections above. In 2013, our project group has organized a series of MCD's in a large healthcare institution in and around Amsterdam. Based on these MCD's, we are developing a moral compass, that provides first-line ethical support. The first central moral question for this compass is: "When do we respect a client's autonomy and expressed needs and when do we overrule this in order to do well?". This in an issue that professionals frequently struggle with in their daily care practices. With this case study, we will show how this theoretical framework functions in practice. For instance, we cannot analyze a moral dilemma and present the outcome of this analysis, but have to connect this analysis to existing moral vocabulary of the practitioners themselves to be successfully transferred. We will present the preliminary results of both content and form of this moral compass.

How do employees in mental health care deal with ethical challenges?

Bert MOLEWIJK, Medical Ethics Professor, Centre for Medical Ethics, Oslo, Norway

Working in mental health care and dealing with coercion inherently entails dealing with ethical challenges. Many assume that addressing ethical challenges in the right way will contribute to a better cooperation and quality of care. There is a growing amount of literature on how ethical challenges are dealt with within the context of Clinical Ethics Support (CES). Surprising little is known about how employees in mental health care deal with ethical challenges when there is no or not yet any form of CES. Understanding how employees deal with – or may pass over - ethical challenges is important in order to support the employees and to develop CES in mental health care in a fruitful way. METHOD Within a larger project in which moral case deliberation (MCD) was about to get implemented, a focus group interview study was executed (before the actual implementation of MCD took place). Seven focus groups interviews at seven different wards/departments in three Norwegian mental health care institutions were conducted. Interviews were audio-taped and transcribed into 220 pages. 65 health care multidisciplinary professionals (including management) participated. Structured qualitative analysis of the answers to the question 'How do you deal with ethical challenges in situations where coercion might be at stake?' were performed in four rounds. Interviewees received no further description of what 'ethical challenges' are. RESULTS Qualitative analysis resulted in several main categories. Employees differed strongly regarding the main category 'how frequent do they deal with ethical challenges'. Some said they do it never, some said they do it all day. Others said they do it only implicitly, while others said they do it only explicit after a crisis situation. Regarding 'in what kind of arena do they deal with ethical challenges', they mentioned various ad-hoc and regular meetings: debriefing between shifts, regular team meetings, educational or training days and peer review. Only one interviewee reported about a case that was brought an ethics committee. Quite some interviewees reported that they lack specific arenas. The participants seldom used any specific method or a moderator/facilitator role. They explicitly mentioned that their communication and meetings on (ethical) challenges could profit from more knowledge on and a specific method for dealing with ethical challenges. Some reported a need to discuss this more in a multidisciplinary context. Common barriers for dealing with ethical challenges were: time, lack of a method, a culture in which deliberating together is unusual, and a lack of an overarching view. CONCLUSIONS In general, there seem to be little moments or methods in which employees explicitly deal with ethical challenges. Furthermore, most of the challenges are perceived and discussed as 'challenges', not as 'ethical challenges'. Employees reported a need for knowledge about and a method for dealing with ethical challenges. It was not automatically clear what should get conceived as 'an ethical challenge' and 'dealing with', both conceptually and practically. This also touches upon the normative question what an appropriate dealing with ethical challenges entails. These findings stress the need for normative and conceptual clarification at the one hand and concrete educational support for employees at the other hand. Some suggestions on how to do this will be presented.

ROOM 6: Considering adolescents: children or adults?

Chair: **Florence VEBER,** MD, Necker Hospital, AP-HP, Paris, France

"Living on the Edge": Patient and Family Experiences of Benefit and Burden During and After a Life-Threatening Event

Gail GELLER, Bioethics Professor, Johns Hopkins University, Berman Institute of Bioethics, Baltimore, USA

The unpredictability and life-limiting nature of chronic, progressive pediatric neuromuscular conditions raise significant physical, emotional, spiritual, social and ethical dilemmas for affected individuals and their families, and create special challenges for the health care team and for ethics consultants. Duchenne Muscular Dystrophy (DMD) is the most common genetic, neuro-degenerative disease worldwide. Boys with DMD manifest symptoms in pre- and early school years. Although advances in respiratory and cardiac management allow DMD patients to live into their 20's, their burden of disease is high, commensurate with the amount of weakness, and they often undergo major operations or require extended hospitalizations for routine childhood illnesses or life-threatening events. Patients living with chronic, life-limiting conditions such as DMD, represent an expanding population with unique obligations and opportunities to understand their lived experience and address the ethical challenges that accompany their care. We recently completed a large grant designed to (1) explore the unmet needs of patients and families affected by DMD and their clinicians, and (2) integrate ethical principles and practices into the management of these patients and families. We developed a number of video documentaries based on interviews with patients, families and members of the interdisciplinary team of clinicians, and designed educational interventions/curricula using the videos as triggers for discussion. During the course of this project, one of our participants experienced a life-threatening event which signaled the next stage of decline in the course of his disease. He spent 2 months in the pediatric intensive care unit (PICU). When he returned home, he and his family had to adjust to what they describe as a "new normal". We had the extraordinary opportunity to capture, on film, the impact of this transition in disease progression on the patient and his family. In this session, invoking the tool of film to analyze ethical challenges, we will screen this documentary, called "Living on the Edge" (which is subtitled in French). Following the film, we will reflect on the ways in which benefits and burdens of care are represented and addressed during and after a PICU admission, and explore the ethical challenges raised by this experience. We will pay particular attention to the involvement of adolescents in decision-making about their care, and highlight the opportunities for more systematic involvement of ethics consultants in these difficult cases.

Ethics Issues in the Transition from Paediatric to Adult Care: Sharing Canadian Experiences

Hannah KAUFMAN, Bioethics Consultant, Toronto University, Centre for Bioethics, Toronto, Canada

Transitions within and between healthcare settings are an emerging trigger for ethics consultation but typically focus on transitions of geriatric patients from acute care to an alternate level of care setting such as rehabilitation, long-term care or palliative care. For individuals with medical conditions that span from adolescence into adulthood, the ethical issues of transition from pediatric to adult care bear importance but are often overlooked (Kaufman et al, 2010). As adolescents change physically, emotionally and cognitively, their medical and psychosocial needs change, often as their legal decision-making status changes. However their voices may be unheard due to assumptions about capacity, previous and often long-standing patterns of obtaining information and consent from surrogates and lack of knowledge of adolescent brain development. Further, health implications of suboptimal transitions include anxiety, distress, and delays in access to required health services. In this presentation, we will first describe ethical issues, values, principles, obligations and strategies related to transitions for this age group. Some illustrative ethical issues include: a duty to treat adults who are in the pediatric system in an age appropriate manner; decision-making around age of transfer for special populations, such as those with autism spectrum disorder, developmental delay or rare childhood diseases in which there is little expertise in the adult healthcare system. We will then present briefly the results of (1) dedicated organization-wide transition programs and inter-organization processes as innovative, integral and ethical strategies for safe and successful transfers to adult care, (2) a national (Canadian) workshop to stir reflection on transition in youth with neurodevelopmental disability (Racine et al, in press), (3) themes emerging from interviews of families of youth with complex medical and developmental needs and (4) examples from transition programs from across Canada. We hope to spark international discussion on regional and national experiences in this area.

Advocating for the Adolescent's Voice in Advance Care Planning

Jessica MOORE, Assistant Professor/Clinical Ethicist, Texas University, MD Anderson Cancer Center, Texas, USA

Advance Care Planning (ACP) reflects the ongoing process of communication among patients, families, patient representatives, and healthcare providers where prognostic information, therapeutic options and patient's life goals, values, and wishes for further treatment are better understood and addressed to honor patient preferences, along the continuum of care. Opportunities to participate in Advance Care Planning can afford the parents of children with a progressive, fatal illnesses greater ease that their child will receive care that is consistent with their values. Ideally, this care should be focused on addressing the needs of the whole patient as person in a family centered manner. Likewise, the fears and anxiety of the minor patient can be relieved by their inclusion in these discussions, in an age appropriate manner. Often decision-making for pediatric patients emphasizes the experience and authority of the physician and the parents, while the patient's experience maybe suppressed. The best medical decisions in pediatrics are made when the rights and obligations of the physician, parent, and patient are all considered. It is important that the patient's voice be heard, in an age appropriate context, and given weight; especially in the case of life-threatening illness. We will discuss, in a case-based fashion, the benefits of giving parents and adolescent patients opportunities to participate in ACP conversations together; thereby, empowering the minor patient. We will review the factors that should be considered when deciding to disclose information to a pediatric patient in order to include them in ACP conversations; as well as, some of the reasons why many families and physicians may exclude minors from these conversations. The most commonly cited barriers to inclusion are culture, faith tradition, protection, and hope. Finally, we will discuss the Ethicist's role in facilitating these conversations and providing recommendations for practical solutions. Ethicists are uniquely positioned to ensure all of the stakeholder voices are heard. This may even require particular advocacy for the minor patient as a stakeholder whose wishes should be considered in the determination of medically appropriate, ethically sound, patient and family centered care.

Adolescent Refusals to Participate in Decision Making: Should We Require Informed Assent?

Rebecca YARRISON, Clinical ethics Professor, Kentucky University, College of Medicine, Lexington, USA

In the extensive literature about pediatric assent, there is near universal consensus that minor patients should be included in the decision-making process commensurate with their ability to participate. There is also a strong consensus that minors should be told all necessary information about their injuries or diseases and what to expect from treatment, and that this information should be communicated in an age-appropriate way. There is still debate about what counts as "necessary" information, but at least there is discussion about that issue. An issue that has received little attention is what to do if the minor patient refuses to hear this information and declines to participate in decision making. Discussions about barriers to hearing the child's voice have focused on debates about capacity and strategies for handling requests for non-disclosure from parents, but there is little guidance on what to do if the child does not want to participate. This presentation explores this issue by describing the case of an adolescent with osteosarcoma for whom hemicorporectomy was suggested as a possible treatment. The patient declined to participate in decision making about the procedure and declined any information about hemicorporectomy beyond a very basic level of information. She would agree to whatever decision her family made. In one sense, she expressed her wishes and gave her assent to the procedure. However, the procedure would severely affect her quality of life and activities of daily living and would require her compliance and active participation in recovery. Minors who decline to participate in decision-making are expressing a choice about what information they would like to receive. However, for some treatments and procedures, uninformed assent (simple assent), even with the informed permission of the parents, cannot be ethically sufficient to perform the procedure. In that case, the challenge for caregivers is whether to accept the patient's refusal of information or to require fuller participation in decision-making. Factors that would determine whether simple assent or truly informed assent should be required include: the patient's age and maturity; the nature of the proposed treatment; the reversibility of the proposed treatment; the required level of cooperation and participation in treatment or post-treatment rehabilitation; and the overall consequences of treatment.

ROOM 7: Questions of Ethics, a documentary from Anne GEORGET

Chairs: **Denis BERTHIAU,** Law Professor, Paris-Descartes University, Paris, France
François-Xavier GOUDOT, MD, Avicenne Hospital, AP-HP, Paris, France

An unusual immersion in the heart of the Center for Clinical Ethics at Paris's Cochin Hospital. The Center counsels physicians, patients, or patients' families dealing with ethically complex medical issues. Where are the boundaries between "beneficence" and "non-maleficence"? How can a situation be clarified, so that dialogue and trust prevail? How can a balance be achieved between divergent points of view, between the patient's autonomy and his or her family's grief? Filmmaker Anne Georget concentrates on the Center's private discussions and interviews surrounding five cases, analyzing them in all of their complexity.

15h30-15h45 COFFEE BREAK

15h45-17h15 PLENARY SESSION:

Clinical Ethics and Justice: patients' interest versus society's interest

Chair: **Didier TABUTEAU,** Director of the Health and Political Sciences Department, Sciences Po Foundation, and Co-director of the Law and Health Institute, Paris Descartes University, Paris, France

Conflict between individual and collective interests? Reflections on a clinical ethics study about decisions to terminate a pregnancy

Marie GAILLE, Philosopher, Research Director, SPHERE, CNRS- Paris Diderot University, Paris, France

Clinical ethics, as theorized, taught, and practiced at the Center for Clinical Ethics at the Cochin hospital in Paris, is based on the use of four conceptual tools (the principles of autonomy, beneficence, non-maleficence, and justice) to analyze the cases referred to the center. In any given situation, these principles do not necessarily apply as a whole. Secondly, some of them may apply separately to the same situation, orienting the ethical decision in one direction or another. Thirdly, principles may conflict with one another. The reflections we are going to develop here focus on this third type of situation, more specifically a case where the principle of autonomy seems to militate against the principle of justice. In international clinical and medical ethics literature, a significant number of precedents for settling this type of conflict refer to questions of resource allocation. In France, however, for reasons related to the history of the healthcare system and the way it is financed, the question of resource allocation is rarely encountered in the practice of clinical ethics. Patients and doctors are strongly committed to the principle of equal access to healthcare. They resist the idea that the cost entailed by a treatment, let alone a comparison of the costs entailed by various treatments, could ever enter into an evaluation of its ethical evaluation. Nevertheless, the principle of justice is extremely operational in French clinical ethics. The cases reviewed over the years have allowed us to define this principle more clearly. It includes taking the viewpoint of the healthcare team and the hospital as an institution into account, and, in many cases, of the democracy as a whole, i.e. the "collective moral attitude" on a given subject, as well as the "values" that a society has a duty to defend and promote. From 2011 to 2013, the center for clinical ethics, Véronique Fournier, Géraldine Viot (geneticist), and myself coordinated a study (the data analysis is under way) called "The decision to terminate pregnancy following a diagnosis indicating a genetic disease." I would like to qualify the conflict between the principles of autonomy and justice in such situations, and evaluate the importance of the conflict in this type of procedure. I shall start by saying that in French bioethics literature, there are often suspicions that individuals make decisions for "eugenic" reasons, and that there are some grounds to suspect "social eugenics."

33 patients, single women or couples expecting a child, were interviewed at a prenatal diagnosis clinic in Paris. Did their statements attest to a conflict that could be described in terms of eugenics? When they decide to terminate a pregnancy, is it appropriate to remind them that they are challenging a value – the acceptance of difference – they would advocate, under other circumstances? Should the principle of justice prevail in this case, to the detriment of respect for autonomy? Or, on the contrary, is it more ethical to privilege patient autonomy, although it contradicts the collective interest in the acceptance of difference? At a first reading, the interviews show great convergence between the motivation put forward as a parent and as a member of society. Moreover, the interviews do not massively confirm the suspicion that eugenics is a motivation. If any conflict does exist between the interests of individual patients and the collective interest, the clinical ethics investigation indicates that the crux of the matter is elsewhere. On the one hand, the interviews show how complicated it is to apply the principle of justice. It is not the realm where the individual confronts "shared values." France is an immigrant land with a culturally diverse population. Individuals from different cultures evaluate their social trajectories and the act of starting a family differently, depending on their background. Moreover, because the principle of justice implies taking the viewpoint of the medical team into account, it would be appropriate to see whether in some cases, the conflict might reside in a disagreement between this team and the patients.

The patient's inaudible voice in the imperious clamor of necessity

Aissatou TOURE, MD, member, Ethics National Committee, Dakar, Senegal

Can the voices of southern-hemisphere patients be heard, amid the deafening clamor of the needs and emergencies in emerging nations? Over the past few decades, the patient-doctor relationship paradigm has evolved in Western countries. Is this evolution compatible with the problems that currently need to be solved by healthcare systems in developing countries? The ratification of international treaties and conventions enshrining the rights of the individual, the adoption of new laws aimed at the rights of the patient, reforms to the healthcare system establishing the participation of patient organizations, citizens' groups, health committees, and communities as stakeholders: all of these phenomena are signs that the healthcare community is increasingly aware of the need to give greater attention to patient needs, and committed to achieving that goal. Nevertheless, any analysis of medical practices in a socio-economic context characterized by poverty, illiteracy, insufficient accessibility to quality healthcare (or to any healthcare at all), along with the burden of infectious diseases which need to be managed through massive public-health intervention policies, and different social representations and referents for disease, will show that the theoretical attention is difficult to transform into a real consideration of the concepts of patient autonomy, effective participation in healthcare policy choices, medical decisions, etc. True, the voices of patients, as a group, is beginning to be heard, via the patient organizations that are being set up. They are even members of the board of certain public hospitals. The voices of users, as a group, within the framework of consumer unions, of citizens' committees, of parliamentary representatives, and community representatives, are probably increasingly audible, and are being accounted for in the elaboration of healthcare policies. But too often, the feeble voice of the single patient, in his individualism, vulnerability, and often his poverty and isolation, is inaudible, overpowered by the supremacy of the doctor's white coat. Could autonomy be a luxury, accessible only to those who have the power to choose? An agent engaged in ethical reflection would obviously, spontaneously, and probably indignantly reply No! But he or she would then have to confront the problem of how to overcome the obstacles so that theory becomes reality. Development in every aspect is undoubtedly one of the major issues. Likewise, training the healthcare system agents, making our societies aware of the need for benevolent attention, devoid of condescendence and respectful of the voices of the most vulnerable, is a necessity.

Clinical Ethics in Psychiatry: which risks for individual discrimination?

Stella REITER-THEIL, Medical Ethics Professor, Co-founder ICCEC, Basel, Switzerland

Psychiatry raises multiple ethical questions. One of the most prominent ethical issues is the challenge to treat patients whose autonomy is impaired due to psychiatric illness with full respect; another one regards the considerable vulnerability of psychiatric patients; moreover, there is a societal tendency to marginalize psychiatric patients. fter decades of efforts to humanize psychiatric practice and to provide respectful and supportive care and an equitable access to the health system, how can there be risks for individual discrimination and which might that be? I will argue that the issues of stigmatization and discrimination of psychiatric patients are not merely 'sociological' hypotheses, but possess clinical relevance and evidence. This will be illustrated by examples from Clinical Ethics Support (CES) in a large Psychiatric University Hospital. On the background of the literature and clinical experience from ca. 30 cases of CES in Psychiatry in the last 18 months, risks for individual discrimination are identified, e.g.: (i) a child whose psychiatric disorder is under-diagnosed, i.e. underestimated or misjudged resulting in unspecific or insufficient treatment and delayed help; (ii) a multi-morbid adult psychiatric patient in need of help for severe somatic illness facing suboptimal medical care; (iii) an incapacitated elderly psychiatric patient, not (any more) capable to adjust to a "Psychiatry-with-open-doors", running away repeatedly with disruptive consequences. It will be analyzed how the interests of "third parties" interact with these individual patient risks. In the literature ethical issues in Psychiatry are addressed such as problems with patient (lack of) autonomy, prevention of harm, use of coercion, handling critical situations like suicide as well as societal pressure through marginalization on their patients. Psychiatry itself also has problems with a lack of public appreciation. Ad hoc strategies for solving ethical problem in Psychiatry often seem to rely on interpreting legal paragraphs, maybe more than in somatic medicine. Healthcare professionals in Psychiatry are acknowledged for their interest in communication that may help tackling ethical problems. Conclusions: Psychiatry – and the medical system – should acknowledge justice issues such as stigmatization, marginalization and discrimination. CES can help to articulate them explicitly and to highlight specific need for change.

Is the Patients' Empowerment a factor of Social Justice?

Yann LE CAM, EURORDIS Chief Executive Officer, Vice Chairman of the EU Committee of Experts on Rare Diseases (EUCERD), Paris, France

17h15-17h30 COFFEE BREAK

17h30-18h30 KEY-NOTE CONFERENCE:

Which place for the patient's voice in the reflection of a National Ethics Committee?

Jean-Claude AMEISEN, President, Consultative National Ethics Committee (CCNE), Paris, France

With the participation of: **Claude RAMBAUD,** President, Collectif Interassociatif pour la Santé (CISS), Paris, France

Chair: **Eric FAVEREAU**, journalist, Paris, France

Saturday, april 26, 2014

9h00-11h00 PLENARY SESSION :

Voices having hard time to make them listened in the health care system

Chair: **Dafna FEINHOLZ,** Chief of the Bioethics and Ethics of science and technology section, sector of Social and Human sciences, UNESCO, Paris, France

Birthing A Market -Commercial Surrogacy In India: An Exploratory Study

Nadimpally SAROJINI, Social scientist, Founder and Director of Sama (Resource Group for Women & Health), New Delhi, India

While official statistics on the number of surrogacies being arranged in India are not available, anecdotal evidence suggests a sharp increase. Reproductive tourism in India alone is "valued at more than $450 million a year and was forecast by the Indian Council of Medical Research (ICMR) to be a six billion dollar a year market in 2008" Within this, surrogacy particularly commercial surrogacy—the practice of gestating a child for another couple or individual through the use of ARTs and in return for remuneration—has drawn much attention and raised several social, legal and ethical concerns. Commercial surrogacy is often portrayed as a 'win-win' situation, seen to give 'desperate and infertile' parents the child they want, and poor surrogate women the money they need. In the Indian context, factors such as lack of regulation, comparatively lower cost with regard to many of the other developed countries for instance Canada, UK, USA, less waiting time, possibility of close monitoring of the surrogates by the commissioning couples, availability of a large pool of women willing to be surrogates, infrastructure and medical expertise comparable to international standards, have together created a conducive environment for the expansion of the industry. A wide array of actors catering to clientele at the domestic as well as international levels has emerged. The close links between fertility / surrogacy centers and religious institutions was also highlighted by the research. ART clinics, healthcare consultants, hospitality industry, travel agencies, law firms, surrogacy agents, tourism departments, and hostels have sprung up to provide diverse kinds of support services to further the growth of the surrogacy industry. The presentation delves into the complexities and negotiations in surrogacy through the narrativized version of interviews conducted with a surrogate in Delh and Punjab states of India by Sama resource group for women and health. The narratives aim to document the experience of surrogates; to theorize their subject location the socio-economic background of the surrogates who enter into surrogacy arrangements has a direct bearing upon their choice to enter as well as the terms of the arrangement, and situate this within current debates in feminist theory and political economy. Although it is impossible to encapsulate the complexity of surrogacy with few narratives, by documenting their experiences, we attempted to explore the lives, locations, motivations and concerns of women who do surrogacy. As surrogates push the boundaries of women's labor from the private to the public, from care to work, the accompanying objectification and rampant exploitation of their bodies poses serious threats to their health and rights. Questions of agency and autonomy complicate the feminist position/s on surrogacy. Is the body a legitimate resource? What are the ethical and political challenges in surrogacy? Is the surrogate agent or victim? Does surrogacy give the "noble gift" of a baby from one woman to another, or is it "dirty work", stigmatized and secretive? In constructing the identity of women as surrogate mothers, commercial surrogacy as an area of inquiry does raises difficult ethical questions with regard to 'choice', autonomy, medicalization of women's bodies, rights of the surrogate, etc., with no easy answers.

The inaudible voice of the patient in Africa: How ethics can improve hospitals there?

Félicien MUNDAY, MD, Bioethics Professor, President, National Ethics Committee, Kinshasa, Congo, RDC

We intend to show that in Africa, patients experience disease in a different sociocultural, spiritual, medical, and politico-economic context from patients in industrialized countries. The difference in contexts of the patient's life shold lead to a different perception of the mission assigned to clinical ethics. We want to make it clear that in Africa, clinical ethics must commit to much more specific goals, compared to clinical ethics in Europe. This is all the more true in light of the muffled or inaudible voice of the patient in Africa. In fact, this voice is syncopated and stifled, because it is fragmented, shattered by the many players intervening in the healthcare space. To wit, in Africa, definitive medical decisions about the birth of a child, the last hours of life before death, about diseases requiring long-term treatment, and incurable diseases, are influenced and determined by several different members of society, more than the patient himself. A patient who has one of these diseases, or who is about to die, is treated first by the guardians of taboos and social norms. In other words, the heads of his clan, the sorcerers, the makers of fetishes and the folk doctors, implicate themselves and act upon the patient, who usually submits to their authority. Because the patient then goes away to the hospital, he is treated healthcare professionals. Vulnerable, illiterate, unschooled in medical science, he is treated like a child. He has no say in medical decisions. Next, on the hospital premises, pastors from various churches pay him visit after visit. They endow the disease with spiritual meaning. In this respect, again, the patient is deprived of his autonomy. Again, he has no say in his decisions. He has a duty to deliver himself to the Eternal, the real healer. After the patient has been treated by sociocultural experts, biomedical experts, and religious experts, he confronts the physical and administrative environment of the hospital. The patient faces difficult sanitary and accommodation conditions. He is continually being asked to pay for small services. The patient and his family face the hospital administrative agents, who consider him to be a vulnerable person. He has nothing to decide. Therefore, he cannot be consulted. What can clinical ethics do in relation to the difficult situation of the African patient? Is it not true that ethics must broaden its scope, and go farther, drawing upon its dynamic source as a branch of philosophy. Primarily, ethics will serve as critical analysis. The African clinical ethicist will challenge authority, questioning the relationship between disease and socio-cultural beliefs, the relationship between disease and religions or religious beliefs, the relationship between disease and healthcare professionals, the relationship between disease and governmental authorities, personified as hospital administrators. The rights of the patient in Africa require theorization and practice. For that reason, it is urgent to set up ethics consultation offices, or better yet, clinical ethics consultation offices. Steps must be taken to humanize healthcare in Africa.

Disablilty, Ableism and emotion

Debjani MUKHERJEE, Psychologist, Bioethicist, Donnelley Ethics Program Director, Rehabilitation Institute of Chicago, Chicago, USA

"Around the world, persons with disabilities face physical, social, economic and attitudinal barriers that exclude them from participating fully and effectively as equal members of society." In healthcare settings as well, people with disabilities often experience marginalization and report being disrespected and devalued. In this presentation, a clinical ethicist and psychologist who has been working with people with disabilities for over 20 years will use critical disability studies and social psychology theory to examine clinical ethics practice. She will describe some of the tensions and difficulties with being "heard" as a person with a disability in the healthcare system and primarily focus on attitudinal barriers to inclusion, including ableism and emotion. She will also examine clinical ethics concepts such as substituted judgment and best interest in the context of disability. Finally, she will consider how clinical ethicists can facilitate equal treatment of people with disabilities, when they may share the biases that are in the dominant culture.

Being a good listener would not be easy but be essential for elderly care professions

Ryutaro TAKAHASHI, geriatrician, Tokyo Metropolitan Institute of Gerontology, Tokyo, Japan

An 84-year old woman came to see my rehabilitation clinic as she wants to improve her walking function. She repeatedly admitted to the hospital due to chronic heart failure and her cardiac function is severely declined. Medical stuffs and care manager recommended her to move to the institution. She is living alone and receiving in-home help services 3 times daily. I asked her the reason why she wanted to stay in her home. She answered, 'because I am living that place for more than 50 years and want to die there if possible'. She said that it was the first time for her to be asked the reason. I don't know it was the first time or not, but I think it is true that we often judge medical or care planning without asking him/her actually. The other important aspect is complexity in conversation with them. A 79-year old man, who is diabetic for a long time and has an end-stage kidney complication, said to me, 'I don't want to receive hemodialysis, and want to be seen by you when I am dying'. Several minutes after, he expressed his hope that new therapeutic procedure would be found in the near future. The newest procedure or death with dignity, which does he want to choose? We see older people who have long-lasting complaints, such as pain, fatigue, etc. An 88-year old woman is living in a retirement home for 25 years. Fifteen years ago, she fell in her room. After that, she complaints fatigue and sick feeling. Medical checks were carried out repeatedly, and couldn't detect any diseases. She was getting offensive, and stuffs faced difficulty to deal with her. She was finally diagnosed as multiple chemical sensitivity (MCS). I interpreted her complaints as an expression of adjustment process to her aging. I don't know MCS is correct or not. Above all, it is crucial that we listen to patient's voice itself. In the presentation, the comparative study on awareness and thoughts about end of life care among Japanese older people examined 2013 and 16 years ago in an acute geriatric hospital will be introduced. I also mention results of the recent our study on promoting advanced directive in community-dwelling Japanese people. We found a great gap between passive minded situation (questionnaire survey) and independent minded expression (recording their willingness in a note). The majority of participants seems to be confused when they actually write down their willingness.

Getting them to listen to me: arguments users use in mental health services

Tim GREACEN, User representative, Georges Pompidou European Hospital, Director of the Maison Blanche Research Unit, Paris, France

User groups in the public psychiatric sector claim that patients who consider their rights are being infringed have difficulty getting clear answers to their questions. This presentation describes a project developed by the French National Federation of Users in Psychiatry (FNAPSY) and the Maison Blanche Hospital Research Unit. The project analyses the subjects of complaint and the arguments used in 350 letters received by the director of a large psychiatric hospital in central Paris and then analyses feedback from a focus group with user representatives and different professional groups concerning effective means of (a) creating a more powerful user discourse and (b) taking into account user complaints and suggestions and acting upon them to improve health service delivery. Typical subjects of complaint included wanting to leave the hospital, wanting to change doctors, bad living conditions, personal possessions disappearing, the use of force, threats and fear, and being aggressed. Complaints from relatives expressed worries about continuity of care or requested copies of medical records. The focus group underlined the gap between the legal treatment of letters of complaint and the provider response on ground level in the services, with different categories of personnel using different sorts of arguments to reply to the letters and proposing different response strategies.

11h00-11h30 COFFEE BREAK

11h30-12h00 PRESENTATION OF THE PROJECT WHICH HAS RECEIVED THE SCHWAGER AWARD

Chair: **Stella REITER-THEIL,** Founding member of ICCEC, Professor of Medical Ethics, Basel University, Basel, Switzerland

12h00-13h00 PLENARY SESSION:

Selected pieces, ICCEC 2014:

Chair: **Céline LEFEVE,** Philosopher, Georges Canguilhem Center, SPHERE, Paris Diderot University, Paris, France

With: **Samia HURST,** MD, PhD, Bioethicist, Geneva, Switzerland
Sadek BELOUCIF, MD, Avicenne Hospital, AP-HP, Paris, France
Bert MOLEWIJK, RN, Bioethicist, Amsterdam, Netherland
Anne-Marie MOULIN, MD, Philosopher, CNRS-INSERM, Paris, France

13h00-13h30 CLOSING SESSION:

Véronique FOURNIER, president, Scientific Committee ICCEC 2014
Georges AGICH, Cofunder ICCEC, Texas, USA
Rosamond RHODES and **Robert BAKER,** ICCEC 2015, New York, USA
Jean-Loup SALZMANN, President, Conférence des Présidents d'Universités, President, University of Paris Nord, Paris, France

Marisol TOURAINE, French Minister for Social Affairs and Health Care, Paris, France (to be confirmed)

POSTERS SESSION (1)

Posters exhibited from Thursday April 24 noon to Friday April 25 noon.

SESSION 1A:
The voice of patients whose competence is discussed

Providing advice on clinical ethics to MAIA-Lille case managers as a means of amplifying the voice of dependent elderly people living at home

Sabine DELATTRE, MAIA Lille agglo, Lille, France

The MAIA is the national mission for the integration of services providing assistance with care and autonomy to elderly people in their own homes. Regional agencies were set up in 2011, for the purpose of forming local coalitions of the professions involved in providing services to older people living at home but gradually losing functional autonomy. The forces of professionals from the fields public health, social medicine, and social assistance can be concerted thanks in particular to a new profession, that of the case manager, who is in charge of providing the most appropriate services to elderly persons in their homes. Subject of the presentation: The MAIA Lille Agglo, which opened in June 2013, decided to support the pilot program and three case managers with methodological advice on approaching the clinical ethics of the program, bringing in consultants from the Center for Medical Ethics (CEM) at the Université Catholique de Lille. This initiative is twofold in purpose. The primary goal is long-term work alongside case managers on the situations they include in MAIA's active case file. Gradually, the consultants will clarify the criteria that make a home care situation complex and, more broadly, will define the scope of the new case-management profession. However, my talk will concentrate chiefly on the second goal: reflection on how to promote the new approach to providing services by forming a team of professionals, in order to amplify the voices of elderly, dependent patients being cared for at home. Method: To answer this question, an exploratory study will be set up. In the six months to come (November 2013 - April 2014), MAIA will hold six clinical ethics meetings to analyze twelve situations, selected and presented by the case managers. Their selection will be based on the space allowed for the elderly patients to expresses their preferences, values, wishes, and needs. The point of these evaluations is to clarify the degree to which the efforts of the case manager make it possible to respect the patients' voices, or to highlight the problems that keep the patients' voices from being heard. By identifying the obstacles, MAIA hopes to improve the overall situation. For that reason, the study will be comprehensive and qualitative. Goals: Detailed analysis of the twelve home-patient situations should enable us to outline an initial response to the question of how a MAIA service can help make patients' voices heard; and to suggest some specific guidelines for improving the practices implemented by healthcare professionals providing services to elderly persons at home. The second phase of the study (summer 2014) will consist of opening up these thoughts and guidelines to general discussion, within the framework of workshops on "Case Management" and "Life Project and Journey" organized by MAIA Lille Agglo. The preliminary findings of the exploratory study will be presented at the Paris conference.

ULYSSES directives in addiction: what part should ULYSSES play in their creation?

Joanne GORDON, researcher, biomedical ethics, Lancaster University, Newcastle Under Lyme, United Kingdom

This paper addresses the following two questions, generated by the proposed use of Ulysses directives in revolving door addiction: (i) What type of decision-making process should be involved in the creation of a Ulysses directive? (ii) What is the patient's role in this process? It has been suggested that Ulysses directives could be useful in the management of revolving door addiction, as illustrated in the following narrative: X is a revolving door addict. He/she engaged with treatment services six times in the last two years. On each occasion X achieved a short-term remission followed by disengagement and relapse. He/she wants to request that treatment be delivered in the future regardless of any anticipated resistance. Ulysses directives are a type of advance directive. Advance directives provide a mechanism whereby individuals can decide in advance what they would like to happen in the future should they be unable to participate in clinical decision-making and instruct healthcare professionals accordingly. A typical advance directive would be an advance refusal of blood products by a Jehovah 's Witness. In these so-called op-out directives the default action of the healthcare professional is to intervene. The patient's voice in the advance refusal shouts 'Do not intervene.' These directives are usually enacted unilaterally, i.e. without the input of healthcare staff. Ulysses directives, in contrast, represent advance requests for treatment in a context where healthcare professionals are generally obliged not to provide it. For example, when a patient with an addiction disengages from treatment healthcare professionals cannot usually administer any medication or restraint without that individual's valid consent. Given this, a unilateral Ulysses directive would be of little use. It must be created collaboratively. Much of the literature has focused on the capacity of Ulysses directives to provide patients with a voice in the future when they resist or refuse intervention. There has been little attention paid to the role of the patient's voice in the creation of this type of advance directive. This paper will address this research gap in the following way: (i) In the first section, I will briefly describe a range of shared decision making models identified in recent work by Sandman and Munthe. (ii) In the second section I will present my argument for a 'principled negotiation' model of shared decision making in this context and outline the steps that may be involved in this process (iii) In the final section I will explore how clinical ethics support services could facilitate this type of shared decision-making process. I contend that clinical ethics involvement would be crucial to ensure that (i) the norms of respect for autonomy and beneficence are adequately addressed, and at a practical level (ii) to help circumvent future referrals from addiction specialists asking 'Should I comply with this directive? when a patient inevitably resists or refuses the stipulated intervention.

Patients Always Have a Voice: Ethical Decision-Making for Patients with Diminished Capacity

Nicholas KOCKLER, Senior Ethicist, Providence Center for Health Care Ethics, Portland, USA

Many patients, especially the elderly and those with mental illness, have diminished or no capacity to participate in decision-making. Consider, for example, the patient who influenced by her paranoid schizophrenia refuses to allow her aortic stenosis to be managed by catheritization with valvuloplasty even though her prognosis is excellent if she does so and poor if she does not. Another example is the patient without any next of kin who has dementia, diabetes, and osteomyelitis with gangrene who needs an amputation of his foot and rehabilitation but who refuses. A last example is the medically fragile young adult with severe developmental delay who simply cannot understand the importance of dental extraction of a mesioangular impacted wisdom tooth. In these and similar cases, patients often can still express, sometimes very forcefully, their will – through words or deeds: the patient who wants to leave the hospital; the patient who makes threatening physical gestures when staff approach; or the patient pulls out a nasogastric tube or, worse, a PEG tube. Moreover, a surrogate may agree to an intervention or care plan justified by the patient's "best interests" however that plan may be contrary to the patient's "expressed" will. Is it fair to the patient to simply follow the surrogate or, in the absence of a surrogate, to simply move ahead based on a presumption that the patient must be protected from his or her lack of capacity? In other words, is the consent of a surrogate or the benefit of a clinical plan sufficient to ethically justify moving ahead regardless of the patient's expressed will? This paper will address the ethical significance of the incapacitated will of a patient and offer a methodology for caregivers to use to address the ethical issues of these types of patients who need, but do not want, beneficial care. It will do so by exploring the ethical rationale for keeping the decision as close to the patient as possible and will offer a decision aid used in our ethics consultations to guide decisions and care planning for patients with diminished capacity.

Prevention of violence in psychiatric inpatient care – Aspects of ethics and safety in patient and staff encounters

Veikko PELTO-PIRI, MA PhD Student, Psychiatric Research Centre, Orebro, Sweden

There has been a lot of research on risk assessment and prevention of violence. Violence prevention has usually been based on empirical research, emphasizing evidence-based knowledge, but often not taking into account the value-based aspects. We believe that the prevention of violence is not only a question of method, but also a question of values. To succeed in prevention we need to be aware of views and values of patients and staff regarding what constitutes a safe environment. Accordingly, we base the project on a preliminary theoretical model including ethics, encounters and safety. Violence in psychiatric inpatient care is a serious problem for patient and staff security. Concerns about risk of violence may in itself cause daily psychological distress for patients and staff members. An unsafe care environment with risk of violence also leads to poorer quality of care. It has been shown that verbal aggression, without physical violence, can cause back pain and other pain among staff, especially in wards where the support from management is weak. Patients may feel unsafe because they find it difficult to understand the ward rules, have a fear of other patients, are worried that staff may use coercive measures, or notice that staff is afraid of another patient. A therapeutic relationship creating a sense of trust is important in providing a safe treatment milieu. Research suggest that the creation of a safe care environment where patients rarely need to be subjected to coercive measures is the most effective approach to violence prevention. In order to create this safe environment, we need to understand when patients and staff consider a ward environment as safe or what makes them to perceive it unsafe. There is a need for further research since there is relatively little done on patients' and staff's own perceptions of the ward environment. With this poster we are looking for international cooperation to start a European project focusing on aspects of ethics and safety in encounters between patients and staff in psychiatric inpatient care. The project can also be extended to other types of institutions in the medical or social field. Aim. The aim is to understand what kind of environment patients and staff consider as safe or what makes them to perceive it unsafe. The specific research questions are: 1) How do patients and staff describe a safe or an unsafe ward environment? 2) How do patients and staff describe experiences of violence? 3) What suggestions do patients and staffs have to prevent incidents of violence? Method. Our preliminary research design is to study these questions with multiple methods monitoring the ward milieu; site visits, questionnaires and interviews with patients and staff members in psychiatric inpatient care. The critical incidence technique is one possible way to identify and analyse successful and unsuccessful experiences of dealing with incidents of violence and to get concrete suggestions about how to prevent incidences of violence. Expected results. This project can give a basis for realistic strategies for prevention of violence with an ethical approach and a contribution to international research on psychiatric inpatient care.

Which ethical problems do healthcare professionals raise in Moral Case Deliberation concerning patients whose voices are impaired?

Dara RASOAL, Phd student, Nursing, Orebro University, Orebro, Sweden

Background. Ethical problems are frequently encountered by staff members working in healthcare settings. One set of difficulties concerns patients who have trouble expressing themselves or where staff members wonder whether patients' expressed desires correspond to their best interests. Various forms of collective moral reflection have been developed to discuss and deal with these kinds of ethical problems. One approach, Moral Case Deliberation (MCD), aims to support healthcare professionals in managing ethical problems that arise in clinical practice through the discussion of individual patient cases. In this study, we aim to describe the ethical problems staff members bring to MCD, in cases where patients' voices, as a result of their illness, are impaired. Methods. This study takes a descriptive and qualitative approach. Data were collected from MCDs in various Swedish healthcare settings: three dialysis wards, three internal medicine wards and two municipal care wards. In each ward, sessions occurred once a month, lasting 60 to 90 minutes, with personnel present from a range of specialties. The MCDs were led by an external trained facilitator with an ethical background. Where advance approval was obtained, the sessions were recorded. Transcripts available for about 50 patient cases; a large sub-set of cases were selected which concerned patients who had a diminished voice as a result of physical or mental illness. Transcripts from the sessions were analysed inductively using thematic content analysis. All extracts from the transcripts relating to the study aim were coded and classified. Preliminary findings show that many problems which were raised by staff involved managing conflicting interests, between the patient him/herself, other patients on the wards, family members and staff. While this work is in progress, early analyses showed that the problems related to a range of biomedical ethical issues, such as autonomy, nonmaleficence and integrity. In addition, a large group of the cases concerned professional comportment, values, beliefs and the management of emotions. Conclusions. The wide scope of the discussions showed that healthcare professionals faced a large range of ethical problems in their daily practice. Within institutional constraints, staff members struggled to balance the impaired voices of individual patients with the voices of others.

Facilitating comprehension and intelligibility for persons with cognitive impairment in decision-making processes

Liv THALEN, Speech and language pathologist, Department of Speech Pathology, Karolinska University Hospital, Stockholm, Sweden

Facilitating comprehension and intelligibility for persons with cognitive impairment in decision-making processes LivThalén 1,2 &Ing-Mari Tallberg 1,2 1 Department of Speech Pathology, Karolinska University Hospital (Huddinge) Stockholm, Sweden 2 Division of Speech and Language Pathology, Department of Clinical Science, Intervention and Technology, (CLINTEC), KarolinskaInstitutet, Stockholm, Sweden In health and social care contexts also cognitively impaired persons need to make vital decisions between treatment opportunities and life changes, e.g. acceptance of help or moving to a nursing home. Previous research has shown that cognitive impairment renders difficulties in understanding what possible risks and benefits different courses of action have. Furthermore, the demented person's impaired communicative ability reduces the interlocutor's possibility to understand the view of the demented person and thereby increase distress. Following that, it was considered significant to find ways for enhancement of the demented person's ability to understand a situation and make a decision and also to enable these persons to express his or hers views in a comprehensible way. The aim of the present study was to investigate a method for support of communication and designed for people with dementia in decision-making situations. The hypothesis was that a visual frame work for communication could enhance demented persons' ability to a more active participation in a discharge meeting at a geriatric ward. Two groups of demented subjects participated in the study, one group consisted of subjects that were provided a visual support method (Visually Supported Group; VSG, n =15) and another group of subjects constituted a matched control group (CG; n = 15). The subjects were recruited from a geriatric memory ward and they were all examined and diagnosed in accordance with a comprehensive assessment protocol. The visual support method "Talking mats" used a frame with pictures possible to arrange within it. Pictures represented opinions and super and subordinated concepts. After one or two initial sessions where the method was introduced and practiced it was established if a subject was capable to use the visual support in a conversation. Each subject was then randomly selected to belong to the VSG or to the control group. Those subjects that belonged to the VSG group got one extra session before the discharge meeting. With help of the visual frame work the VSG subjects expressed their views regarding their personal abilities to take care of themselves and receiving different types of help at home, with other words topics that often arise during a discharge meeting. The CG subjects participated in the discharge meeting in accordance with the ward's ordinary standards. Afterwards, everyone that took part in the meeting (the subjects, the staff, and the relatives) evaluated the subjects participation and communication on visual analogue scales. Preliminary results showed that the demented subjects were able to use the visual support and that both the patients, relatives and the staff appreciated the opportunity to make the voices of the demented subjects heard. Quantitative results from the evaluations will be further analyzed and discussed during the presentation.

SESSION 1B:
Clinical ethics and patients' and proxies' perspectives

How to improve access to patients' medical chart from a clinical ethics perspective?

Laurence BRUNET, jurist, Centre d'éthique clinique, Cochin hospital, AP-HP, Paris, France

France did not legally grant patients or their representatives direct access to their medical records until 2002. At that time, to comply with the provision, most hospitals merely set up a purely administrative procedure whereby they mailed a copy of the records to the patient, without reviewing what prompted the request on a case-by-case basis. In proceeding this way, certain departments have the feeling they may have been counterproductive in relation to expectations. This is particularly true of ICU departments, because the requests for access to the records they handle often involve patients who died, or for whom the stay in intensive care was experienced as a tragedy. They wondered if something besides a need for purely medical, technical information was driving these requests for access to the hospital files on the patient. The Center for Clinical Ethics at Hôpital Cochin was solicited by the intensive-care unit at that hospital to carry out a joint study, for the purposes of learning more about what motivated the requests. The point was also to see if it would not be more appropriate to communicate this type of information in a different way. A monocentric, qualitative study was carried out, made up of two randomized arms of 25 patients. For Group 1 (G1), medical records were mailed out according to the usual procedure. For Group 2 (G2), the medical records were turned over to the applicant in person, following a meeting with the doctor from the ICU and in the presence of a researcher from the Clinical Ethics center playing the part of "ethics ombudsman." Regardless of group, the applicant was later interviewed by phone, to evaluate his or her satisfaction with the procedure, in relation to the motivations that prompted him or her to request access to the file. Currently, the study is still underway. 21 requests have been fulfilled for G1 and 9 for G2. The qualitative results are not yet available, but the findings of the study are already interesting, in the early stages:

- Carrying out a research study involving a subject of ethical concern in daily clinical practice is apparently a good way for a clinical ethics center to integrate itself into the hospital and make the healthcare staff more familiar with the contributions the center can make;

- Clearly, a non-negligible number of requests for medical records are driven by motivations other than a need for medical information alone. Of the first 30 cases included in this study, about 1/3 of the requests were actually prompted by other considerations. This proves the standard administrative response is not really appropriate, and that it would be quite useful to succeed in identifying requests that deserve a more personal response than an envelope in the mail, devoid of any proposal to discuss the case further.

- Mediation by a pluridisciplinary team of researchers seems to be appreciated by both the applicants and the hospital staff. Applicants are relieved to have an opportunity to get more feedback on questions that linger in their minds. Even if they met with the doctors on the spot during the stay in the ICU, they may have been unable to formulate the questions, either because they feared it was inappropriate or because they were voiceless with anxiety and grief. As for the doctors, they discovered the value of having a benevolent, neutral "translator-mediator" to rely upon in meetings with a patient or family who might be angry at, or distrustful, of the hospital staff for one reason or another related to their grief.

Doctors wish to tell the truth! However patients do not know the truth!

Nilufer DEMIRSOY, Research Assistant PhD, Faculty of Medicine, Department of History of Medicine and Medical Ethics, Eskisehir Osmangazi University, Eskisehir, Turkey

"Why do we see human beings as bundled and swaddled" M.de Montaigne In terms of both ethics and law, doctors are liable to inform patients about diagnosis, prognosis, treatments suggested, and risks and benefits of the treatment. In ethical terms, doctors are required to provide information, without prejudicing the principle of beneficence and preserving the balance of benefits. Some doctors tend to hide information or delay the provision of information, assuming that the patient may get harmed or the information may have devastating effects on the patient. In most cases, such a decision is influenced by cultural differences, ethical approaches and moral values. These decisions pose problems in both ethical and legal terms. For patients, knowing the correct diagnosis is important in order to ensure the continuity of treatment, improve life quality, use limited resources effectively, and get support and protection from family members. The present study is designed to identify the approaches and attitudes of doctors to telling the truth about diagnosis and treatment, and of patients to knowing the truth. Questionnaire surveys were administered to inpatients and doctors responsible for their treatment in order to identify their viewpoints on telling the truth and learning the truth, after the permissions required were taken from a Research Hospital and the Board of Ethics. For the construction of the questionnaire, a group of 10 specialized doctors were asked to reply to 10 open-ended questions related to the aim of the study, and their replies were formulated as items comprising negative or positive statements. The statements were transformed into 5-point Likert scale. The survey was administered to 30 doctors and 30 patients that represent the sample before the survey form was finalized. The validity and the reliability of the questionnaire were calculated (Reliability coefficient Cronbahα: 0.82). The survey form, with high scores of reliability and validity, was distributed to doctors and patients with appropriate instructions. The data of this study was collected from 166 physicians working in the clinics of both surgery and internal medicine, and 435 inpatients receiving treatment in these clinics. The doctors employed in surgical clinics support more strongly the priority of the right of patients to get information than the doctors working in internal medicine clinics. Furthermore, 66.4% of the patients wish to be informed correctly about the diagnosis of their disease. In sum, patients have the right to know the truth regarding the medical facts about their disease, diagnosis, prognosis and all components of the treatment process. As revealed by several studies conducted in countries where there are no precise rules about informing patients of their disease, there have been many dilemmas and differences about telling the truth to patients. More importantly, because of failing to deal with each patient holistically and individually, there are no clear and precise approaches to telling the truth to patients and many conflicts arise in medical settings.

Perinatal death: Understanding the parents' grief and helping them with the mourning process

Marie-Ange EINAUDI, MD, neonatology, Espace Ethique Méditerranéen, Marseille, France

Perinatal grief is a separate category of mourning, with which the general public is unfamiliar. We started with the hypothesis that families who have lost their baby at the hospital need more support. The goal of our research is to understand all of the ramifications of such an event. By describing the experience of a few parents, we hope to identify their needs better in order to provide guidelines for caregivers. We asked 12 parents who had experienced a perinatal death to participate in a qualitative study consisting of semi-directed interviews and questionnaires. The answers were then grouped by theme (their child's history, the family situation, the entourage, hearing the news, saying farewell, parental feelings: criticism or regrets, follow-up) and analyzed with regard to the principles of biomedical ethics. In particular, this study showed how difficult it is to apply the doctrine of parental autonomy in perinatal medicine.

Bioethics and Child and Family Relations Working in Concert to Ensure the Pediatric Patient's Perspective is Heard

Rebecca GREENBERG, bioethicist, The Hospital for Sick Children, Toronto, Canada

Patient representatives have been employed in hospitals in the past as a means of addressing patient complaints. With the impetus of adopting an approach to family centered care that supports the experiences and voice of the patient/family it became evident that much more needs to be done to promote family centered care and ensure that it is practiced throughout the hospital. The Hospital for Sick Children (SickKids) in Toronto, Canada therefore developed The Child and Family Relations (CFR) model (formerly known as patient representative service) as a vehicle for communicating the patients' voice. Since the inception of the new model, two years ago, CFR has built a strong partnership with the Bioethics Department (BD). This paper will discuss how CFR and the BD work together to address ethical issues and through collaboration better ensure the patient voice is heard and integrated in health care decision making. By providing coaching and education, CFR staff aim to build the capacity of staff at SickKids to manage patient and family concerns at the point of care, and establish and maintain positive relationships with patients and families. Through these relationships, CFR has the opportunity to promote the voice of the patient/family and help to improve the quality of care and service delivery. As much of the work of the CFR team has an ethical component the team works with the BD to address ethical issues. Such issues include: the tension between patients' needs and teams' recommendations, the best interests of the child, the role of the child in their health care planning, and the limits to privacy and confidentiality. The BD brings ethical expertise to this partnership, including the newly developed I-CASE (Identify, Context, Alternatives, Select, Evaluate) Ethics Decision Making Tool; a tool that is used to assist health care teams, staff, patients and families work through ethical dilemmas and ensure all voices and perspectives are considered. The I-CASE Tool helps to identify stakeholders (e.g. the patient/family) and ethical resolutions while the CFR team works to deeply explore and promote the patient's/family's voice. The CFR team also brings expertise in communication and conflict resolution. Bringing together the skills, tools and models of CFR and the BD have resulted in better consideration of all stakeholders' views and timelier, amicable resolutions of ethical dilemmas. This paper will describe: 1) the CFR model, and 2) the BD processes for addressing ethical issues (i.e. SickKids Ethics Framework and the I-CASE Ethics Decision Making Tool) and how they are used in concert to address ethical issues and help advance the patients' voice. Case based examples will be used to explore ethical issues related to patient autonomy in the pediatric setting.

The sufficiency of information given patients in terms of informed consent and its impact on patients decision

Dilek GULEC, Hacettepe Univesity, Ankara

Informed consent implies the approval of the patient that he accepts the medical intervention in his own free will after that the doctor gives sufficient information about the intervention in question, its risks and benefits. Studies show that doctors have insufficient information about "informed consent" which is an indispensable component in the scope of legal obligations in terms of doctor-patient relationship nowadays. In this study we aimed at clarifying the information level of patients, sufficiency of the information given to patients concerning the medical intervention and the impact of such information on the decision process of patients. 570 patients, who underwent a surgery intervention in three hospitals, i.e. a university, a state hospital and a private hospital in Ankara, participated in the related survey. In the preparation of the said survey, previous surveys carried out in the same field have been taken into consideration. Firstly, ten patients were surveyed in order to see the insufficiencies and make the necessary amendments. The survey has been carried out in face-to-face meeting. Frequency bar charts, chi square test and one sample test have been applied in the evaluation of the data obtained. The survey showed that 40,5 % of the patients have never read the written approval form and 60,8 % of them think that the form is signed for the exoneration of the doctors and hospitals. While 47,3 % of the patient participating in our survey declared that their own doctor has been the source of information in this respect, 16,2 % of them indicated more than one doctor as information source.

What do the patients say "Behind the Screen"?

Dorte Elise Moller HOLDGAARD, Nurse, Ethical and Quality Adviser, University Hospital of Aalborg, Aalborg, Denmark

What do the patients say "behind the screen"? Background and motivation for the project: At the University Hospital of Aalborg, Denmark, every second year we ask for the patient's opinion and experiences with the hospital. For the period of one month all the patients get a questioner sent, and around 55 - 60% answer. In 2012 57% of 231 patients, who went through our Neurosurgical Ward in August/September were asked for their opinion about our out-patient ward. But, do we always know what the answers indicate? Some of the answers made us doubt about, what would be the right action to take, to make things better for the patients. For example what does it mean, when 39 % tells us, that they have got no information about their illness and the treatment, when we know, that all the patients in our neurosurgical ward, get written information and a talk with the doctor about the offered treatment? And as it was not the only wonder we had, we decided to investigate the area. Purpose: We wanted to get more precise information from the patients and if possible, their relatives, so we could change our procedures in clinical practice more precisely, or get at better focus for the changes. Method: In our outpatient-neurosurgical-ward we asked 6 persons, who earlier had gone through a lumbar disc operation (slipped disc), if we might invite them to a talk about their experience with the path through the system. We took the whole path, as we knew about problems with the discharge. The patients were asked to invite their relatives, for the interview, and they all did that. So we gathered 10 persons for a 2 hour-interview, as one patient had to cancel. As it was not a scientific investigation, and as we also wanted to gather experience with the method, the patients were asked "by chance" You could say. Before the interview, the patients and their relatives were informed about the procedure and their rights. They were all invited the same day, as part of the method was to let the patients inspire one another during the interview. In Denmark we call this group-interview for a "Focus-group-interview". As leaders of the process, we chose two, one person whom the patients knew from the ward, and one they did not know. The last person was mainly the mediator of the process, and a professional coach. When the group of patients and relatives talked about their experiences, 10 persons from the staff, - nurses, also from the operating theater, secretaries and doctors, were listening, sitting in the background. After about ½ an hour`s interview with the patients and their relatives, the mediator turned around, and asked about the opinion of the staff: "What have You heard and what will You go home and change"? Finally the mediator turned back to the patients again, to hear the patient thoughts and opinion after listening to the staff. Results: We got more précis information to act on, and we can tell about that and give examples on the conference. In the general view you can say, that you go from the quantitative perspective to the qualitative. Perspective: The managers of the hospital has found the process worth to imitate, so now all the wards at the university hospital has to use this method at least once a year, "To hear the Patients' Voice". At the Neurosurgical Ward we have now planned a focus-group-interview with patients, who have been operated for a benign tumor, - so at the ICCEC- conference we can tell from that interview as well.

Do patients prefer male or female physicians/counselors during family planning, pregnancy and birth process? A sample from Turkey

Nurdan KIRIMLIOGLU, Assistant Prof. Dr. PhD, Faculty of Medicine, Department of History of Medicine and Medical Ethics, Eskisehir Osmangazi University, Eskisehir, Turkey

Background: The relevant literature shows that there is a complex relation between physician gender and patient satisfaction. In some studies, while the patients having female physicians were found more satisfied, some others were reported to be satisfied with their male physicians. The aim of this study is to investigate women's preferences regarding the gender of the team that provides health care in gynecology and obstetrics, and to discern the factors affecting their preferences. Methods: The study participants are 324 females ages 15 to 49, who consulted any of the family planning units of the hospitals or health centers for a family planning method or for the continuation of the method they were already using. Three hundred eighty-eight participants (49 in the informed group and 339 in the uninformed group) responded to the questions in the questionnaire related to the process of pregnancy and birth. Results: Two hundred forty two (74.69 %) of the counselees who participated in our study preferred female physicians/counselors. One hundred sixty patients (47.2 %) among the uninformed group and preferred the same-sex health staff for medical care, and 16 patients (32.6 %) who were among the informed group and expressed the same preference, reported that females would understand them better, and they would be more comfortable with female physicians. Conclusions: In the provision of family planning counseling services, counselees prefer female counselors because they have good communication skills. Patients prefer female physicians due to their shared experiences of pregnancy and birth.

On the need for ethical reflection at various stages of male fertility preservation prior to sterilizing treatment

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Self-preservation of sperm is prescribed to patients about to undergo treatment liable to make them sterile. These men are confronted simultaneously by news of a serious disease and the recommendation to take a preventive measure concerning the quality of their lives in the future, the main purpose of which is to enable them to father children. How do patients find the skills to cope with the diagnosis, on the one hand, and on the other, this projection into the future? How does such intensive medicalization of private life affect the patient's voice? We wondered about the experience of these men, ranging in age from 11 to 80, after hearing testimonials made by these patients drawn from the memory of caregivers. Must patient autonomy be varied as a function of the time frame, the different moments in this this journey, the information given or withheld, the age? Must acts of maleficence be accepted? Often sperm preservation is imposed brutally and urgently, at a given time, T-zero, in order to be beneficent much later, at T+2, T+5, T+15, T+20 years. Is the patient's voice still genuine, when the fear of a serious and sometimes deadly disease overpowers any ability to listen to the information given about this preventive procedure? Patient testimony leads us to believe that counseling is essential, as a means of making this pact with the future understandable and meaningful. It suggests a different sort of listening, to overcome the anxiety aroused by the diagnosis of a serious disease, and to enable the patient to accept the right information from the outset, and then later, when the sperm is restored to the patient for the purposes of procreation with his partner. The medical approach alone may not suffice, especially when the man's request raises questions with healthcare staff regarding his health, his age, the age of his partner, the welfare of the child, etc. Technical progress, paired with societal developments, drive us to delve ever deeper with ethical questioning, in order to reach a fairer analysis of the various requests. It is impossible to be satisfied with rules and recommendations for best practices, for they must continually be re-thought. The patient's voice is the compass that guides us, and we must continually readjust our course.

The Importance of the Patient Voice During Rounds

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Rounding is an integral practice of medical care, it serves the dual purposes of providing medical education and it guides inpatient care. This practice is primarily used as an opportunity for the medical team to review the patient's condition, and to develop and coordinate a plan of care. Despite being a key component of how physicians go about formulating a patient's plan of care, there is significant variability of hearing the patient's voice on rounds. Little has been said of the involvement of patients and/or family involvement in rounds and the benefits that may result from their involvement. The lack of patient and/or family involvement in rounds is remarkable considering the impact that rounds have on the clinical and emotional outcome for patients. This paper aims to address specifically, to what degree is it important to hear the patient voice during rounds? Addressing this question is important because it has implications as to how involved the clinical team could and should involve a patient in the development of the clinical care plan. This paper will address the practice of rounding, why the patient voice is at times absent from rounds, and it will provide practical methods that could be utilized to ensure that the voice of the patient is heard during this integral clinic activity. Hearing the patient voice during rounds is important because there is a potential that the information disclosed by hearing the patient voice can influence the plan of care that the medical team decides to pursue. By including the patient voice in rounds, it provides further context to the appropriate plan of care for a patient. Discussion points that could be utilized during rounds to ensure that the patient's concerns, desires, preferences, will and values are considered during the formulation of the plan of care will also be discussed. Also, this paper will consider how having the patient voice on rounds may compete with the voice of the medical team. Objectives: in an attempt to foster discussion about the impact of hearing the patient voice on rounds, this paper will touch upon the following: 1. Reflect critically on the practice of rounding and its importance to the development of the plan of care. 2. Discuss why the patient voice is at times absent from rounds and the development of the plan of care. 3. Provide methods that could be utilized to ensure that the patient voice is included in this integral clinical activity. 4. Propose discussion points to ensure that the patient's voice is heard and considered during rounds. 5. Consider how the patient voice could compete with the voice of the health care worker during rounds.

SESSION 1C:
Clinical ethics and Public Health

Patients as Bargaining Chips in Industrial Strikes: Some Ethical Reflections

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Industrial strike actions increasingly occur in the health sector across the world, though their frequency seems higher in developing countries. However, healthcare-related strike actions raise several ethical issues. Specifically, this is because they negate the telos of healthcare which involves fostering the medical good of society. On the other hand, entering into the caring professions goes with certain moral obligations in exchange for societal latitude for the power and privilege to practice. Against this conceptual background, this paper examines and explores the ethics of using patients as bargaining chips in healthcare disputes. Employing the notion of reciprocal beneficence, the paper argues that the impropriety of strikes is couched in a deontological understanding of the nexus around the duty to society, patients and professional interests. On this note, the paper advocates a patient-centered panacea vis-à-vis striking a moral balance between perceived conflicts of duty, contextual reality and the needs of the sick. Since healthcare constitutes an instinctual and institutional response to the ubiquitous phenomenon of illness, it is important that health professionals re-examine their moral commitments to society generally and to patients in particular in the light of strike actions.

From consent to choice: the ethical implications of empowerment-based reforms

Luca CHIAPPERINO, life sciences ethics PhD SEMM, European School of Molecular Medicine, Milan, Italy

The ethics of public health is currently facing the challenge of re-evaluating patient autonomy in the light of the political, social and scientific constraints characterizing our societies. Among these, prevention, early detection, and the necessity to reduce healthcare costs for national budgets, play an increasing role within medicine. This state of affairs has led to the development of a whole range of regulatory strategies, across different national contexts, which aim at reforming healthcare. Such initiatives put a strong emphasis on individual responsibility of both the improvement of services offered by the system, as well as the wellbeing of the population. I label such strategies empowerment-based reforms (EBRs). In particular, I focus on how these political endeavors renegotiate power relationships in healthcare (e.g. state/individual, individual/community, professional/patient) for the achievement of: 1) a shift form reactive medicine; 2) a data-driven approach to medicine: integrating information from multiple sources (e.g. genomic profiling, biobanks, environmental and life-style data); 3) citizen-led public decision-making about the healthcare system; 4) patient-centered tailoring of treatments and prevention. The aim of my work is to analyze controversies arising from this paradigm-shift. What I hereby define as EBRs will have different implications for the several stakeholders involved in its development and implementation. As showed above, citizens within EBRs will have access to (and will be required to manage) an unprecedented amount of information regarding their health conditions. Factors such as genetic and biological makeup, life-style behaviors and environmental exposures will be increasing used (by both citizens and professionals) to identify treatment options, to target developing diseases, and to adopt preventive measures for future illnesses. Among the effects that this vision of healthcare is likely to foster, it is thus worth emphasizing how the nature and scope of individual agency will be affected by this paradigm shift, and whether or not this future scenario is an ethically desirable one. In my talk, I identify the range of normative exercises entailed in EBRs, and I present an axiology of empowerment aiming at highlighting the distinctive ethical aspects of this approach. In particular, I identify the different moral entitlements on the side of individual patients called for by EBRs. This analysis is aimed at identifying the potential loci of ethical concern, which could decisively establish an ethically sustainable transition to this model of healthcare delivery. What I will conclude is that, by framing issues related to individual ways, my approach to empowerment could reconcile collective and individual-based conceptions of autonomy and control over health-related quality of life. In particular, I will defend the idea that a citizenship project is underlying EBRs, and that a normative theory suitable for this political endeavor should envisage a new form of agency in healthcare that I will characterize as patient citizenship.

Interpretation of the Narratives of Dialysis Patients on Kidney Transplantation

Omur ELCIOGLU, chief department, History of medicine and ethics, Eskisehir Osmangazi University, Eskisehir, Turkey

The growing need for organ transplantation results in an increase in the interest in organ supply. In terms of organ transplantation, there is a close relationship of meaning between organ donation and organ donor. While "to donate" means give or to present a good or a right to someone without expecting any return; "donor" is the person who donates the aforementioned right or good. As the number of kidneys obtained from cadavers fails to meet the demands at the global scale, the tendency to obtain organs from living donors is expected to continue. Renal transplantation from a cadaver is an ordinary procedure. It is required to foster the "autonomy of donors" in the pool of donors. The "ethical sensitivity" concerning autonomy may suffice to remove donors from being tools and help them adopt transplantation as their goal. One of the most important principles that allow organ transplantation is seeing human beings as a goal. As far as "individual autonomy" is respected, organ transplantation will encourage common sense and hence develop in the community. Donors use their ethical rights, without any harm to their right to live, renouncing something valuable for them but without which they can live. The second principle important in organ transplantation is saving the life of a person who is about to die, without killing anyone. When the purpose is to save the life of a renal patient at the final stage of illness, another "goal" with the same value can be used as a tool to achieve it. The aim of this study is to find out the values and problems used to evaluate the concept of voluntariness from the position of donors and receivers in kidney transplantation. The donors were interviewed through a structured questionnaire, and the interview was recorded. The voice records were evaluated with discourse analysis method, which is used in functional pragmatics. Content analysis is related with not only linguistics but also other fields of science based on interpretation. Content analysis is a research technique targeted at systematic and quantitative definitions. Questionnaires that support this analysis were used. Sample concepts such as moral responsibility, desire to help, increase in self-respect of the donor, pressure from the family, and logic should be taken into consideration diligently in order to detail the voluntariness and choice of the donor.

Patients' values and organ donation in Romania: big discrepancies, big expectations

Cristina GAVRILOVICI, Md, professor in bioethics, University of Medicine and Pharmacy Gr T Popa Iasi, Romania

The fundamental moral significance of organ transplantation lies in its gift - exchange amplitude, in the nature and magnitude of what is given, taken and received. Some would perceive organ donation as a duty of honour, while others would see it as an excessive and extravagant gift. Thinking about organ donation would involve the contemplation of this issue through the lens of altruism, alleviation of suffering, benevolence or charity. According to Eurobarometer survey from 2011, Romania scored one of the lowest regarding openness towards transplantation: the percentage of kidney deceased donors was 6,7 per million population (pmp) in Romania vs 46, 3 pmp in Spain. However, while in Spain the ratio between deceased donated rates and kidney transplants from living donors is 46,3: 6,6, in Romania, this ratio is 6,7: 3,2. This would suggest that Romanians are more in favor on living organ donation than in other countries in Europe. In order to unravel the values that stem behind the reluctance to donate and the preference for living donation we performed a survey among the chronic ill patients. Preliminary results show that Romanian patients perceive organ donation as a way to save a life, an altruistic act, a moral responsibility, an act full of compassion. None of them perceived it as a material compensation. Most of them agree to donate their organs after death and this preference is slightly higher than their preference for living organ donation. Those who are against organ donation invoked insufficient knowledge and fear as main reasons for their refusal. Most of the patients considered even that the explicit consent ante-mortem should underscore the family consent for cadaveric donation from their loved ones. Furthermore, there is a high enough declared level of trust in transplantation team. In conclusion we may say that with such a great perception over the organ donation as a gift of life it is hard to understand why Romanian organ donation rate is the lowest in Europe. Extensive campaigns to support donation, to enlarge the knowledge, overcome fear and increase the trust is needed.

Quality and level of patient voice for assessing new medicines differs widely across Europe

Nick HICKS, director, research department in advocacy communications in advocacy, University of Lyon, Chateaudun, France

Background: International policy directives are calling for patient focused healthcare which uses the patient's unique understanding of living with a medical condition; the patient voice often being communicated to the appropriate governmental decision making bodies and professional societies by the relevant Patient Advocacy Group (PAG) representing sufferers of the illness. For example, within the EMA (European Medical Agency) PAGS follow well established pathways for giving the patient voice in key committees including those responsible for approval and safety evaluation of new medicines. Because of the patient experience in using health care services and technologies it would be expected that national systems would allow relevant patient experience and knowledge to be easily accessed and used in the decision making process for evaluating effectiveness of new medicines. Objective: The research compared the pathways for selecting and using the patient voice in six national European Health Technology Assessment agencies. Each agency studies the medical, social, ethical, and economic implications of a health technology such as a new medicine within the country. Method: We identified websites of six relevant European bodies: England (NICE), France (HAS), Germany (IQWiG and G-BA), Scotland (SMC) and Sweden (TLV). Findings were transferred to Excel spreadsheet and sent to respective agencies for clarification and validation. All HTA agencies but HAS responded. All websites were accessed between August – October 2011. We searched for: (i) How PAG representatives are selected (ii) How they provide input & contribute to the decision making process (iii) How they are supported by HTA. Results: Considerable variation exists in European national systems for capturing the patient voice and the way PAGs are used in HTA new medicines evaluation. Five of the six agencies had pathways for incorporating the patient voice through the PAG. Differences were seen in the following areas: voting rights of PAGS ranging from none to full, full to zero involvement in the decision making process, the method / rationale for selection of the patient group(s) and the level of offered support by the HTA authority to the PAG ranging from dedicated unit to no support. Similarities common to all agencies were seen in the probity criteria for applicant patient groups and their involvement in the planning stages of an assessment. All systems recognized the expert status and value of the PAGS input. Discussion: The study showed that pathways exist but the extent to which the PAG voice is heard, interpreted and valued is dependent on a number of different factors. Some of the pathways appeared to be constructed for more "tick box" or tokenistic type involvement rather than complete equal engagement. The importance of the know –do gap which refers to the tensions between researchers perceptions of the benefit and the actual involvement of PAGS is currently being further investigated in the HTA pathway. The research presented to date suggests that this observation appears more relevant than with the PAG engagement pathways in the EMA. Cultural influences are also likely to be implicated.

"It's a matter that you must do it, even though you suffer": mammograms and pain

Norma MORRIS, researcher in scientific and technology studies, University College London

The mammogram is a well-trusted technology in widespread use for the diagnosis of breast cancer both in the clinic and via mass screening programs. Mammogram use is however not without controversy, with concerns centering principally on diagnostic accuracy, risks from radiation, and 'overdiagnosis', leading to unnecessary treatment. These have taken precedence over concerns about the physical demands of the procedure itself and what that means for patients. Thus disagreements remain on whether mammograms are painful, whether this matters, and (given other pressing issues relating to mammograms) what, if any, policy action is appropriate. On the specific issue of pain the patient voice is surprisingly absent. Ongoiing discussion in the scholarly literature and informal sources however suggest that pain in mammography is an issue in practice and is not without costs. The present paper focuses on this relatively neglected topic of pain in mammography, using both new and published data to probe the strategies, alliances, rationalizations and ad hoc negotiations which are used to manage pain (or contest its existence) at the individual, collective and institutional level, with a particular focus on the forces that, cumulatively, tend to mute the patient voice. The new data presented derives from a qualitative interview study with 85 women enrolled in projects for testing a new diagnostic technology, to explore, inter alia, their views on pain. The participants included 65 women in the UK and 15 in the US, mainly breast clinic patients but including 17 healthy volunteers. Data from these studies were complemented by interviews with some relevant professionals. All findings were in turn compared with professional and institutional views collated from the considerable academic literature on mammogram-associated pain, and the 'grey' policy and guidance literature from service providers and others. Data analysis followed standard qualitative methods, with assistance from specialist qualitative research software. We found a notable mismatch between, on the one hand, patients' and professionals' reported experience of pain in mammograms (see quote in title) and, on the other hand, published guidance on the procedure from ostensibly authoritative bodies, both public and private ("pas très agréable… .. mais pas douleureux)". The conceptual and political influences shaping views on pain are discussed, and the ambiguities resulting from divided loyalties (among both patients and staff) between perceived demands of duty and repugnance to physical insult. It is concluded that the resultant balance of powers between individuals and institutional actors is such that, despite demonstrable tensions, the ambivalence, particularly of women patients, towards suffering pain will ensure that protests remain muted, and unlikely to stimulate system change or lead to the emergence of a united patient voice for change. Rather than aim for collective action, patients and front-line professionals are more likely to deploy local strategies to help manage individual pain and anxiety and promote compliance. There is nonetheless scope for policy strategists and clinical ethics bodies to take action. This might take the form of instigating practical measures to recognise and support such local efforts through promoting programs of pain mitigation and further research on technological innovation and refinement of existing systems.

Growing ethics from the ground up: A case study of a community based disability network

Lisa MOY, social assistant, University of the Fraser Valley, Vancouver, Canada

While ethics and ethical practice in social work is the focus of much attention in social work literature, there is little discussion about the ways in which ethical issues are multiply situated and jointly tackled across private/public/community/institutional realms. Despite the abundance of research and resources that highlight the work of institutional ethics groups (for example, hospital ethics committees or university ethics boards), the absence of practice examples and academic literature on community engaged ethics groups is a marker that the work of those who 'grow' ethical conversations in the community is worthy of academic attention and professional curiosity. Utilizing theories in feminist post structuralism, this case study examines the various ways ethical tensions, community alliances, and social work across disability are visited and framed by participants in a community based ethics network comprised of self advocates and family members, community advocates, social workers and medical ethicists. Via critical discourse analysis, the research project examines hegemonic and alternative discourses about ethics and disability and, more specifically, the ways in which these discourses position notions of 'community' and so-called 'non professional' engagement. In addition to shedding light on the ways in which discussion about ethics needs to be fore grounded in community contexts, the purpose of this research is also to better understand the complexities and nuances of building alliances and community partnerships with persons with disabilities and those that support them. Ultimately, this case study explores how—in situating conversations about ethics in the community (versus within more structured or rigid institutions)—the boundaries and meanings attached to 'community', 'disability', and 'ethics' shift and stretch. The conference presentation will conclude with reflections on the implications for social work education and practice discussion of a reconsidered intersectional approach to ethics and community building.

Ethics Consultation in Cell Therapy Research

Kayo TAKASHIMA, researcher in medical law and ethics, public health care department, University of Tokyo, Tokyo, Japan

Patients and their families, especially those who have fallen victim to an incurable disease, may display a greater willingness to undergo a novel form of treatment, if it has a small possibility of success, even if the treatment is still undergoing development in clinical research. In this case, how can we support the respect for patient autonomy? In the framework of clinical research ethics, clinical research aims at social benefit rather than the personal interests of patients. If a patient enrolls in the research program anticipating benefits, this expectation is called Therapeutic Misconception (hereafter TM). However, if no treatment is available for a particular disease, we might be inclined to admit that the research could be like a warm candle in a dark forest. Furthermore, Innovative therapy (hereafter IT), which means conducting research to have intention of therapy, could create higher expectations than other forms of research. However, with regard to patient autonomy, it would be the treatment rather than research that would create expectations, despite the fact that they understand it is not a treatment that has been approved by regulation. As IT, for example, the world's first-in-human (hereafter FIH) study of induced pluripotent stem cell (hereafter iPSc) therapy research was approved in July 2013 in Japan. iPSc innovative therapy has received widespread attention in recent times because it is one of the key elements of the Japanese Healthcare and Medical Strategy, with 110 billion yen of public funding allocated for research support over the next decade. Masayo Takahashi, project leader of the FIH iPSc therapy project at Riken in Japan, has expressed her concerns about excessive expectations for research by patients and society. Ethical consideration must be given to how these issues should be treated. We then consider that it may help to encourage patient participation in stem cell therapy as IT to obtain accurate information and also to develop a good relationship between researchers and patients to ensure the success of their trial. Therefore, we believe that it would be beneficial to respect patient autonomy when they have a strong desire to participate in IT. In this poster, we will discuss how to support patients who participate in IT from the point of view of ethics consultation.

The contributions of a Regional Hematology Patients' Committee

Sophie TRARIEUX-SIGNOL, clinical research engineer CHU de Limoges, Limoges, France

In 2002 and 2004, the French Ministry of Health Hospital Treatment Department published memoranda on setting up Patients' Committees within hospitals dispensing treatment for cancer. In October 2008, the Hematology Unit at the CHU in Limoges created a Patients' Committee which, by late 2009, had been assigned to cover the whole region. A multidisciplinary steering committee was established and a charter was drafted, defining the composition of the committee, its role, and its operations, in order to meet legal requirements. The Committee is made up of ten volunteer patients who have survived blood-cancer disease and are no longer being treated. Two members represent patient organizations (France Lymphome Espoir, Ligue contre le cancer). It is coordinated by a clinical research engineer who is a specialist in medical law. The Patients' Committee meets quarterly, having established an agenda ahead of time. It is a consultative body, its mission being to familiarize patients with aspects of treatment and daily routine in hospital hematology units belonging to the Limoges regional treatment network. Its goal is to improve patient reception, by providing counseling, if necessary, and information (on chemotherapy, on paperwork for liaising with employers, insurance providers, pharmacists, etc.); supplementary services (hours when the sophrology therapist is available, when the music library is open, etc.), and providing advice on clinical research projects (clinical research protocols, research-nurse services for transplants, qualitative studies, etc.). The Committee's activities do not interfere with the patients' medical treatment. The Committee commissions itself to investigate subjects that appear relevant to its missions, and may also be commissioned by HEMATOLIM healthcare personnel. Depending on the themes set by the agenda, guest speakers are invited, in order to provide the Committee members with all the necessary information. Minutes of the meetings are sent to Committee members, doctors and unit supervisors, the Ministry of Health, the HEMATOLIM Network and the guest speakers. The Patients' Committee works independently from the healthcare team and hospital administration. To date, the Committee has met 17 times, and its members have expressed opinions on a variety of themes. To improve patient reception and treatment procedures, a suggestion box was made by a Committee member. Patients or their families can use the box to deposit suggestions, comments, or criticism anonymously. The Committee has also evaluated the printed or online information pages, intended for patients being treated within the HEMATOLIM network. They looked at form and function: was the information understandable? Did it answer the typical patient's questions? Two doctors have presented two clinical research protocols to the Committee, which studied the informed-consent forms and information notices. Three meetings were devoted to the Léonetti Law on patients' rights at the end of life: the first consisted of presenting the law; the second, of making a poster for patients and their families; the third, of a group discussion of the legislation. The Committee has also discussed the following themes: medical futility, limiting treatment, designating a proxy, the proxy's role, and drafting advance care directives. The chief question is: "In your opinion, who has the right to decide, and why?" Finally, the Committee is consulted on how to use donations made to the department's charity. To conclude, Patient Committees enable patients to participate actively in clinical services. Their members are proof the disease can be vanquished and that other patients can be helped. Even if the viewpoint of survivors of the disease does not reflect that of every patient grappling with blood disease, patients undergoing treatment gain by hearing their views, which complement those of the caregivers.

Patients torn in two directions: if advance directives and organ donor cards coexist

Elias WAGNER, medicine student, ethics, history and medicine theory institute, Munich University, munich, Germany

Post mortem organ donation is increasingly being offered to elderly patients. In Germany, a third of the donors are over the age of 65. At the same time, more than half of this population is known to have advance directives (AD), often documenting their wish to forego intensive care in the case of severe brain injury. It is speculated that the rising prevalence of AD may partly explain the decreasing number of organ donors cards (ODC). We aimed to investigate how many elderly patients have both documents and what their knowledge and attitudes are regarding a possible conflict between both documents. We conducted a self-administered questionnaire survey among the older students program at the University of Munich, Germany. They were approached in 6 different lectures covering topics in science, arts, and society. The questionnaire was specifically devised and piloted. Data was analyzed using descriptive statistics and the chi-square test for inter-group differences. We received 236 out of 350 distributed questionnaires (67%). Mean age was 70 years. The prevalence of ADs was 55%, while 33% had an ODC documenting their consent to organ donation. Nearly a quarter of all respondents (23%) had issued both documents. People with an AD were significantly more likely to also have an ODC than people without an AD. More than half of the respondents (59%) expressed that dying outside of the intensive care setting is more important to them than donating their organs, and 59% thought that a dignified dying is jeopardized by intensive care measures. Only 29% would consent to intensive care treatment in the case that brain death was expected within the next 3 days, while 53% would do so in the case of already suspected brain death. Yet, only 31% would allow cardio-pulmonary resuscitation in the latter situation. When asked about their knowledge, only 26% of the respondents knew that intensive care treatment was necessary for post mortem organ donation. This result did not significantly differ between those who had an ODC and those who did not. Conclusion. Due to the high prevalence of people with both AD and ODC, potential conflict between both preferences is likely to be a real clinical problem. Most people are not aware that organ donation necessarily entails intensive care treatment and are therefore not aware of this potential conflict. It therefore seems advisable to specify preferences regarding brain death in the AD in a way that suits the complexity of the subject. We also claim that counseling for both ADs and ODCs needs to be more comprehensive and include the information about brain death and intensive care treatment. Clinical ethics consultation can be of great value to tease our which of the given preferences may take precedence in a given clinical situation. In addition, clinical ethics committees should address this difficult topic in both ethics guidelines and education of both the public and the health care professionals.

Pregnant women living with AIDS and undergoing antiretroviral therapy: Clinical and ethical approach

Robert YEMESI, bioethics PhD, public's health school, University of Kinshasa, Kinshasa, Democratic republic of Congo

My talk will chiefly concern a study I carried out on pregnant women living with AIDS (LWA) on antiretroviral therapy (ART) for my master's thesis in the bioethics of public health, in 2012. In the DRC, access to antiretroviral therapy remains a major public-health problem, due on the one hand to the rising number of new HIV/AIDS infections and the shortage of ARTs, and on the other, to social insecurity and unfamiliarity with ethical principles. Until 2011, only 1% of pregnant women evaluated as HIV-positive had access to antiretroviral therapy. In this context, where medication is rare, patients are instrumentalized and deprived of all human consideration. For example, the caregiver does not acknowledge the ability and right of every individual to make her own choices and decisions with regard to medical care. This issue is related to respect for patient autonomy and the right of every human being to self-determination, and the recognition of her dignity and freedom. Often, healthcare providers believe that treatment decisions are the business of the doctor alone, in order to guarantee the welfare of the patient and avoid harming her. In part, this situation can be explained by the caregivers' lack of training in clinical ethics. Likewise, medical paternalism is also to blame. The principles of science (knowledge) and beneficence (true or feigned) are invoked to maintain the authority of the medical practitioner, enabling him to limit the transfer of information, either orally or via the medical record, as much as possible. The doctor, a learned man, knows far better than the patient what is good for her, and therefore can and must choose and decide the best course of treatment, in the name of beneficence or non-maleficence, although he ignores the principle of patient autonomy. Moreover, due to acute shortages of medication, treatment is unlikely, or insufficient to meet needs. This challenge raises an ethical dilemma: i.e., who will benefit from the government-subsidized ARTs, since the supply is still likely to be insufficient to meet the demand. Similar situations are frequently encountered in healthcare facilities in DRC. They are serious challenges to the great ethical principles suggested by Childress and Beauchamp. It would be advisable to draw upon ethical principles to improve the care provided, in order to maximize access to antiretroviral therapy. All of the healthcare personnel and patients interviewed for my study believe that the application of ethical principles to providing care for persons living with AIDS is of crucial importance. It would improve access to medication in a context where there is a shortage of drugs and the community is poverty-stricken. Training in ethics would enable healthcare personnel to stop applying ethical principles in an instinctive, irrational, or random fashion. As long as the various ethical principles of dispensing healthcare are strictly obeyed, caregivers will be prevented from possibly committing social injustice, instrumentalizing the patient, or ignoring her autonomy with regard to her decision to take antiretroviral treatment. Then healthcare for people living with AIDS will become a humanly acceptable right, the product of mutual trust and collaboration between caregiver and patient.

POSTERS SESSION (2)

Posters exhibited from Friday April 25 noon to Saturday April 26 noon.

SESSION 2A:
End of life, futile treatment, advance directives

Advance Care Planning in Nursing Homes – A Systematic Literature Review

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Advance Care Planning in Nursing Homes – A Systematic Literature Review PernilleBruusgaard | Elisabeth Gjerberg | Lillian Lillemoen | Reidar Pedersen Background and aims In many countries, a large and raising proportion of the population dies in nursing homes. Advance care planning (ACP) in nursing homes requires good clinical communication and systematic attempts to elicit the patient's wishes and preferences before it is too late. Inadequate ACP may result in inadequate treatment and care e.g. unaddressed needs and anxiety, lack of information, unnecessary hospitalization, insufficient pain control, coercive measures, conflicts with relatives, and increased moral distress for the professionals. A 4-year research project – started in Norway in 2013 – aims to map, examine, and enhance the existing practices and routines for ACP. ACP and so-called preparatory communication are probably essential to good end-of-life communication and in providing care in the patient's best interest, since most nursing home patients have reduced decision-making capacity when end-of-life care is provided. However, we know that advance care planning is insufficient in many places. This systematic literature review aims to review empirical research – both quantitative and qualitative – on ACP in nursing homes. Methods We did a systematic literature search in September and October of 2013 in the following databases: Medline, Cinahl, Embase and Cochrane Library. We used the PICO scheme (population, intervention, comparison and outcome) and identified two main search components (ACP and nursing homes). For each component we identified relevant synonyms and subject headings in the databases, and used both subject headings and text-words in the search. Any type of scientific method and outcome was included. The search strategy was checked by a research librarian. After reading the abstracts we selected articles to be read in full text. Finally, we selected articles to be included in this review. The selection was based on a pre-defined set of inclusion and exclusion criteria. In addition, some articles were included through ancillary check (reference check, hand check, and expert advice). All abstracts and the full text articles were independently assessed by at least two of the authors. Results At the conference the following themes will be presented based upon our systematic review: 1. What kind of ACP-models have been studied in nursing homes? 2. The main outcomes and significance of using ACP. 3. Barriers and promoters of ACP. 4. Methods and design used to study ACP. Conclusions Preliminary analysis indicates that there are relatively few scientific articles that evaluate ACP in nursing homes. The importance of shared decision making also in nursing homes, and the reported results in the articles included in this review, indicates that there is a need for both ACP and for more studies using varied, systematic, and longer-lasting approaches to evaluate different types of ACP in nursing homes.

Barriers to the implementation of Advance Directives in Brazil

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The Advance Directives are recent themes in Brazilian Bioethics. This is because the medicine in Brazil is guided in paternalism and is only from 2009, with entry into force of the new Code of Medical Ethics, the ethics shall accept the consent from the patient as a determinant for medical practice. Thus , despite the Federal Council of Medicine has have published, in August 2012 , resolution 1995 determining the duty of the physician to follow the patient's wishes expressed in the advance directives, issues such as the need for public record, the creation of a National Registry, the form of revocation, determination of validity, and the suspension of nutrition and hydration must be subject to the law on the theme. Moreover, it is known that, even if we have a law regulating the formal aspects of these documents and materials, the Brazilian's culture in not to talk about issues related to death is the real barrier to implementation of this institute. Thus, in addition to a law, is necessary a state program that brings to the Brazilian citizens more awareness of their rights as a patient, specifically in this case, the right to express their wishes for end of life.

Medical futility or obstinacy in treating patients unable to express their will: Analysis of the dissensus between professionals and family

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The French agency on end-of-life issues, the Observatoire National de la Fin de Vie, asked us to do a study on situations in which the possibility of medical futility or obstinacy may impact on patients unable to say what sort of treatment they want. We have developed a grid for deciphering the mechanisms that create this feeling of medical futility or obstinacy. The French law of April 2005 bans doctors from undertaking medically-futile practices, but provides only a broad definition of such practices. When a patient is competent to express his or her will, he or she defines what is reasonable. The patient has the right to refuse any treatment, including artificial life-support. However, when the patient is not competent, deciding whether treatment is appropriate or futile is difficult. The analysis of each case may give rise to significant differences in opinion between medical personnel, other healthcare professionals (nurses and social workers, in particular), and the patient's family. The dissensus between at least two of these three positions fosters suspicion of medical futility. Our grid (Table I) makes a distinction between six different situations. Table I: Analysis of the possible dynamics of dissensus regarding reasonable treatment Doctors Non doctors Family Situation MF1 R+ R+ R- Situation MF2 R- R- R+ Situation MF3 R+ R- R- Situation MF4 R+ R- R+ Situation MF5 R- R+ R- Situation MF6 R- R+ R+ R+: Considers the treatment reasonable. R-: Considers treatment unreasonable. We have also distinguished three categories of situation, depending on public or institutional awareness of them. Category I situations (cat I) are covered by national media; Category II situations (cat II) are conflicts referred to a third-party agency for a decision (national, regional, or local); and Category III (cat III) includes all "ordinary" situations (in reference to "ordinary maltreatment") of which almost no one is aware. Medical futility, or unreasonable obstinacy, therefore appears to be an iceberg, only part of which is visible (cat I et II). The part that is hidden is probably much more disturbing (cat III). Our findings indicated that Type 1 situations are always Category I as well (they make the news). Type 2 situations are much more common (the patient's family refuses to accept the limitations of treatment). "Ordinary" situations seem, in most cases, to be Type 3 or 4 (the nurses/social workers feel that the treatment is unreasonable). Lastly, Type 5 situations, in particular, as well as Type 6, can lead to complicated impasses. This analytical grid sheds new light on the concept of unreasonable obstinacy/medical futility. In order to set guidelines for improved practices that do not subject patients to unreasonable obstinacy, we suggest the following solutions: the recognition that nurses and social workers can serve as watchdogs against unreasonable practices; add unreasonable practices to the checklist used to notify staff of undesirable events; appoint regional facilitation officers assigned to three tasks: acculturation, collecting information, and mediation with regard to implementing the law on "Patients' rights and the end of life." ("Droit des patients et fin de vie").

Self-determination at the end of life: Selected empirical results

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As part of the National Research Priority Program "End of Life" (NRP 67) in Switzerland, we are conducting the research project „Self-determination at the end of life in Swiss law: a critical examination of the legal duty to have to decide for oneself" under the direction of Prof. Dr. Regina Aebi-Müller at the Law Faculty of the University of Lucerne. In Switzerland, the admissibility of medical action today is characterized by the self-determination of the patients. In the course of the past decades, self-determination has become increasingly important on national and international level. A (provisional) highlight in the context of end of life-decisions under Swiss Law can be seen in the regulation of advanced directives on federal level as of January 1st 2013. This new regulation enables individuals to exercise their right of self-determination in the event of their own incapacity to judge or to consent, with a particular focus on decisions affecting the treatment or the discontinuation of treatment in the final stage of life. Does such an emphasis on self-determination truly reflect the wishes and interests of the patients? And: What actions have doctors to take in cases of doubt? In our project we examine whether the current system of adult incapacity law can still - in the context of medical decisions at the end of life - be described as adequate. Decision-making processes that affect the treatment or discontinuation of treatment of patients with advanced diseases in the final phase of their lives, usually prove to be a major challenge. This is especially true if the capacity of patients to judge or to consent is questionable. In order to examine how decision-making processes at the end of life among GPs, hospital doctors and physicians in nursing homes and hospices are actually made, according to what scheme end of life-decisions are taken and what kind of problems medical staff does face in these institutions, an qualitative empirical study in conducted. As part of this empirical survey 45 semi-structured in-depth interviews of 2 hours with doctors and nurses in different institutional and organizational settings are carried out. Currently, the main field phase is running, however, this will be finalized shortly. In our talk we would like to present selected first results of our empirical study, particularly those relating to living wills and the interpretation of ambiguities expressed by patients, as well as those regarding to the role of legal representatives in end of life decision-making. We expect that the study results significantly advance the state of knowledge with regard to self-determination, living wills and adult incapacity law.

When the topic is too difficult: the inhibition of the patient's voice in resuscitation decisions

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The decision whether or not to attempt cardiopulmonary resuscitation (CPR) on an individual is important, and one which will affect many people. It is also difficult: there is no accurate formula for balancing the chances of surviving attempted CPR against the risks of prolongation of dying at a physical cost to the patient (Ebell 2011). Ideally the decision will be preceded by a meaningful discussion between the doctor and patient, so that the doctor understands the patient's priorities, and the patient understands the repercussions of attempting certain invasive treatments. The patient's right to have had the opportunity to discuss, understand and contribute to the CPR decision is an ethically strong one. And yet the evidence suggests that CPR decisions and discussions are ethically deficient on both sides of the Atlantic. In the UK and much of Europe, where patients can refuse but not demand treatments, the 'CPR discussion' is too often not broached at all: one study has shown discussions to be documented only 50% of the time (Fritz 2013), and this is higher than other studies. Observation of clinical practice suggests that the 'discussions' are often merely informing the patient of a clinical decision, with little room for the patient to express an opinion to the contrary or to ask questions about what this decision means for them. Fear of causing patient distress is often cited as a reason for not initiating conversations (Cohn S 2013), but making decisions without the patient's participation may also cause distress. In the US, discussing CPR decisions is often legally required but different problems exist: There is a disconnect between what invasive treatments patients and doctors say they would want and what actually happens. In a case scenario experiment 90% of doctors would not want CPR or invasive ventilation (Wittink 2008); they have seen what it entails, and would rather have a peaceful death. Patients have identified 'avoiding inappropriate prolongation of dying' as a priority of end of life care (Singer P 1999). In contrast, 47% of American hospital deaths occur in the Intensive care unit (Wunsch H 2009). While patients may be encouraged to exercise their freedom to choose treatments in the US, this is not necessarily in their best interests, particularly if they are making a choice based on scanty or inaccurate information. It is possible that doctors have been unable to convey the disadvantages of invasive treatments, or perhaps assumptions are being made about what patients would want, rather than fully exploring their expectations and fears. Too often doctors appear to influence the decision for the patient, and the patient's voice is inhibited. Several factors contribute, some of which can be addressed. We have developed an alternative approach, the Universal Form of Treatment Options (Fritz 2013) which contextualizes the CPR decision amongst other treatments, and is completed for all in-patients. It encourages doctors and patients to focus on treatments to be given rather than on one to be withheld, and shifts the dichotomy from for/not for CPR to considering whether the priority is attempted cure or providing comfort. A patient information leaflet encourages patients to talk about these decisions with their doctors. Doctors reported that conversations were easier to initiate and to maintain; further work is needed to understand whether changes such as the UFTO will help strengthen the patients' voice.

End-of-life communication in nursing homes – experiences and perspectives of patients and relatives

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Background and aims: As in other Western countries, Norwegian nursing home residents are characterized by high age, frailty, and multiple chronic diseases with dementia as the most frequent diagnosis. About 44% of all deaths in Norway happen in nursing homes. The high number of critical events, critical decisions and deaths, make nursing homes places in which systematically eliciting the patient's preferences and values regarding end-of-life care should be carried out before it is too late. An earlier study indicates, however, that the practices and routines for this kind of end-of-life communication is insufficient in Norwegian nursing homes. Moreover, we know little about the experiences and perspectives of patients and/or their relatives on these issues; do they feel that they are given the possibility to communicate their preferences about end-of-life care? How much information and involvement do they actually want? Methods: The data are based on qualitative interviews with 38 patients living in six nursing homes in four counties. In addition, we carried out seven focus group interviews with 60 relatives of patients with cognitive impairments in the same nursing homes. The interviews were based on an interview guide, aimed at gaining more knowledge about how patients and relatives experience central ethical challenges in nursing homes. The interview guide included questions about preferences concerning care and treatment, what kind of medical information they want to have, or want their family members to have, and finally, how much they want to be involved in medical decision-making processes. The interviews were taped, and then transcribed. All the authors independently read and assessed all the transcripts, and the text was then organized thematically. Results: Most patients had not been invited to a conversation about their preferences for end-of-life care. Some said that they would like to have such a conversation, while others said that they don't miss it. Many patients felt that the staff knows them well, and trusted that they probably will act in their best interest. According to the relatives, communication about their family members' preferences for end-of-life care was rare, and they would appreciate that the staff initiated this kind of conversation. A majority of the patients claimed that they want all information about their medical condition, including information of a serious nature. The relatives also wanted to be fully informed about their family member's medical condition, particularly if the patient's health condition is deteriorating. A majority of the patients want to be involved in decision making and to have the opportunity to discuss these questions with their family, but only a minority of the patients had experienced being involved in decision-making processes. When it came to the relatives, very few had talked with their loved ones about their involvement and role in prospective decision-making processes if the patient no longer was able to give consent. A majority of the relatives expressed that they wanted to be involved and be part of the processes of decision making. Conclusion: Few nursing home patients and relatives feel that the staff systematically elicit their preferences and wishes for end-of-life care. Most want to be fully informed and involved in decision-making processes. There are, however, great variations in preferences. Thus; the staff has to ask them.

Representatives´role in the Spanish legal frame

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Representatives'role in the Spanish legal frame. "Ethical question" Within the context of the Mediterranean culture, it is especially important the patient´s and/or proxies' opinion, desires and values. Family is a powerful institution and it is not possible for the healthcare workers to avoid or evade its decisions. In Spain, it is legally demanded not only to ask patients ´relatives, but taking into account what they think, say and demand. Advance Directives allow people to manifest their wishes concerning health care treatment in advance. It is possible to include the expression of the end-of-life decision making, always within the legal frame. The person designed in the document as the representative have a strong responsibility within the decision`s frame. "Approach and arguments" More than ten years ago, the Law 41/2002 that regulates the patient´s autonomy and rights and obligations of information according clinical documentation; introduced the Advance Directives in the Spanish legal frame. It was the Spanish adaptation of the Biomedicine Convention, in order to regulate, for example, end-of-life decisions. With Advance Directives a person of legal age, competent and free, manifests his/her will in advance. This way, the will is enforceable in the moment he/she will be unable to express the health care treatment he/she would like to receive. The future patient can also express in this document the fate of his/her organs or his/her body after dying. The patient may also designate in the same document a representative who will act as a speaker between the patient and the doctor or the health care team; in the case it would be necessary. According with the article 11 in the Spanish Autonomy Law, this is a formal document that is legally binding, either for the health care professionals or patient's relatives. Thus, patients´ proxies have a strong position in the end-of life-decisions and also in the moment that the patient becomes a donor. However, it is not possible to include any wish in this document. Advance directives must not be against the legal system or the lexartis. It is not possible to enforce advance directives related to different medical cases than the ones expressed in the patient's will. "Conclusions" Whether a person's life should be sustained, or whether it can be permissibly be ended, will depend on the doctor's view of the goals of medicine. But even more so, it will depend on the patient's interest and values. The Advance Directives constitutes a useful tool to protect the patients´ autonomy and enforce the end-of-life decision making previously expressed. One way to express and defend patient´s desires it is to include the representative in the Advance Directives document.

What motivates Japanese Older Adults to Communicate Their Preferences Regarding End-of-life Care?

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Communicating with significant others (e.g., family, friends) about one's preferences regarding end-of-life care is the first step in advance care planning, which helps individuals live as they wish until the end of their lives. Our aim in this study was to explore individual factors that make it likely for Japanese older adults to engage in such communication. We conducted a questionnaire survey of outpatients in Tokyo Metropolitan Geriatric Hospital in the last six days of March 2012. Outpatients who consented in writing to participate in this survey filled out a questionnaire during the waiting time with a research staff member available for assistance (e.g., clarifying to the respondent the meaning of words in the questionnaire such as artificial nutrition and hydration). Two items in the questionnaire were concerned with participants' attempt to communicate their preferences regarding end-of-life care; that is, whether they had discussed this issue with their significant others, and whether they had written notes indicating how they want to be cared for in the final days of their lives. Using responses to these items, we classified participants (N = 849) into four categories: both (i.e., those who attempted to communicate both through discussion and in writing; n = 85), only discussion (n = 331), only writing (n = 29), and no communication (i.e., those who had not engaged in either form of communication; n = 404). Participants also indicated (a) whether they had idea whom they want to be their surrogate end-of-life decision-maker, (b) their desirable end-of-life care (e.g., whether they want to rely on artificial nutrition and hydration), (c) their attitudes toward death (e.g., whether they often thought about how they might die), and (d) their background characteristics (e.g., age, sex). Using multinominal logistic regression, we examined which category of end-of-life care communication participants were likely to fall in depending on their individual factors. In doing so, we excluded the category only writing because the number of participants in this category was too small for multivariate analysis. Participants who had idea of their surrogate decision-maker were more likely to be in both than in only discussion (OR = 2.41 [95% CI 1.22, 4.74]; p=.011), and less likely to be in no communication than in only discussion (OR = 0.36 [0.25, 0.51]; p<.000). Also, (a) those who did not want to rely on artificial nutrition and hydration (OR = 0.68 [0.48, 0.97]; p=.032) and (b) those who often thought about their dying were more likely to be in only discussion than in no communication, although these factors were not significantly associated with whether participants were likely to be in both or in only discussion. Our finding that participants who had idea whom they want to be their surrogate decision-maker were more likely to communicate their preferences regarding end-of-life care may help understand how and why Japanese older adults are motivated to engage in such communication. That is, they may attempt to clarify their preferences in order to make it easier for their significant others to make end-of-life care decision on their behalf, rather than to ensure that they can receive their desired care.

SESSION 2B:
Autonomy, free consent, conflicts of autonomy, cultural conflicts, religion

Application of the Rule of Intention (Niyya) to Justify the Patients' Decisions for End-of-Life Care in Islamic Perspective

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In Islamic societies, Islamic law (Sharia'h), established upon the Holy Qur'an and Sunnah, is the legal foundation for all individual and communal matters in daily activities. Besides, bioethics and religion are not two separable elements in Islamic societies, which explains why reference to the Sharia'h plays such an significant role in Islamic bioethics. Any opinions regarding bioethics should remain anchored to the Sharia'h to be legitimate; otherwise, they risk losing credibility, or even losing the possibility of being presented in public. On the other hand, intention (Niyya) is a central concern in Sharia'h as being stated in the hadith "Actions are defined by intentions, and to every person what he intends." In general, Muslim jurists treat intent as definitive of human actions most of the time. Not different from other societies, in Islamic societies, decision making in caring for terminally ill patients is a stressful duty for all involved parties. The attitudes, however, towards the issues vary among healthcare professionals, patients, patients' families, and religious authorities since each party also holds other obligations in addition to common Islamic religion. Therefore, medical professionals must not only make medical decisions upon their professional ethics but also consider and respect for the patients' or their families' preferences and values. Additionally, acknowledging each involved party's intention would possibly justify or oppose to any course of actions in making decisions for end-of-life care. In Islamic perspective, either active or passive euthanasia is disproved while palliative care is approved for its goals to improve the quality of patients' lives and to relieve the suffering. These two ethical issues, along with the rule of intentions (Niyya) and the attitudes toward dying, death, suffering, and suicide will be analyzed on the poster.

Care for the elderly without consent

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Our democratic society has forged social, medical, and legal ways of protecting persons judged to be "incompetent." To deal with these "excessively vulnerable lives," law and medicine have had to bend the presumption that every adult is capable of deciding and taking action for himself. Two apparently incompatible principles must be combined: the ideal of self-determination and the aim of protection. Under the rule of law, the concept of protecting the individual from himself is provocative in itself, because any such protective measure restricts the individual's right to choose to lead his life as he pleases. Protective measures are instituted for persons who, due to their advanced age, mental illness, or cognitive disorders, in particular, are no longer capable of evaluating the consequences of their actions, and therefore incompetent to make their own decisions. It is important to note that the concept of "incompetence" covers a number of multiple realities, as varied as the individuals affected by the classification. It is impossible to reduce incompetence to a generic, global, homogeneous condition remaining the same over time. In all but extreme cases, the individual is never totally competent or incompetent. The idea of incompetence must be applied contingently, to allow for degrees or cycles that depend on the type of illness, as well as the individual: the singularity of the person and the situation in which he or she is encountered. By classifying a person as incompetent and treating him or her as such, we are liable to diminish his or her capacities as much as the disease itself does. Often, the social representation of a disease has a greater impact on the individual than the pathology as strictly defined. Depending on the nature of the illness, for any given individual categorized as "incompetent," there are "good days" when he or she is capable of functioning quite successfully, followed by "bad days" when he or she fails. Because of such fluctuations, the idea is to enable this type of patient to make systematic readjustments to the evaluation of his or her capacities, in order to respect this "fluctuating autonomy," and to bring out and enhance any "residual autonomy" while being mindful of how fragile it is. Best medical practices aimed at protection must strive to enable the individual to maintain his or her identity, or the representation he or she has of this identity. Otherwise, protection will unduly weaken the person's capacity to take part in the decisions concerning him or her. Throughout a person's life, the relationship to and definition of autonomy is an ongoing process of growing and becoming, and functions in a rhizomatic way. Very often, symptoms that involve a loss of autonomy are paired with a new relationship to the self, sometimes unrelated to the illness. They belong to certain phases of life and correspond to a new expression of autonomy. Certain changes in the individual's behavior should not systematically be attributed to difficulties arising from illness. They may also be the product of a new relationship to the world. There is nothing pathological about this relationship; it must be thought of in existential terms. The many realities of autonomy and its expressions in contemporary society result in the absence of formal consensus about the definition. The term "autonomy" is applied to a number of disparate realities, and the way we formulate the concept in our minds is irreducibly multiple and often highly contrasted, from one individual to another. Despite the apparent confusion we observe, is there any coherence to the concept? We will be examining this complexity in an effort to identify the points relevant to drawing the contours of any ethical investigation of providing care to elderly people without their consent.

The pros and cons of integrating spirituality in oncology: What do patients really want?

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A new debate animates today's medical literature: should spirituality be integrated as a dimension of cancer care? Many researchers believe that it should, justifying their position in a number of ways. Some argue that spirituality is a universal part of human nature (Sulmasy D.P.) that requires particular attention within the context of a holistic medical practice; others point out that spirituality can have a positive impact on health (Koenig H.G., 2012); lastly, still others suggest that suffering of a specifically spiritual nature arises (Puchalski C.M. 2009). Nevertheless, significant ethical and epistemological reservations are expressed by other writers. For example, some suggest spirituality should be strictly confined to the private sphere (Sloan R.-P., 2006). How can any form of proselytism be avoided in the caregiver/patient relationship, which is lopsided by nature (Sloan R.-P., 2006)? Won't spirituality be denatured by the normative visions of the medical world? If spirituality is appropriated by hospitals (Jobin G., 2012), it is liable to be distorted (Shuman J.-J., 2003). It is interesting to note that the patients' opinion is rarely considered in this debate. However, we believe that patient input is essential, to set guidelines for such care (Canguilhem G., 1999). We phrased our research question as follows: Do patients dealing with a diagnosis of terminal cancer wish that spirituality be considered as part of the care soon after the disease is diagnosed? As our operational definition of spirituality, we chose the one put forward by Kenneth Pargament, one of the major authors in this field: spirituality is the search for the sacred (Pargament K.I., 2011). Using semi-directive interviewing techniques, we questioned twenty patients coping with cancer diagnosed as terminal, cared for in French public hospitals. The interview grid offered four models (in the form of skits) whereby spirituality could be integrated, in various hospitals throughout the world. The participants in our study were asked to rate each approach according to how attractive they would find it. Definitive findings will be available in December 2013. The purpose of this debate is twofold: on the one hand, to improve patient quality of life, and on the other, to avoid any partiality that is likely to do more harm than good.

Improving the informed consent process in the hospitals in Qatar: hearing the patients' voice through semi-structured interviews

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Background and objective: Informed consent procedures widely used in the Western world are not always adapted to regional customs and the expectations of regional patients and their families. This qualitative study is the first step of a larger project aimed at exploring culturally appropriate ways to obtain fully informed, meaningful consent from patients. The current qualitative study objective is to describe patients' and family members' knowledge, attitudes and behaviors towards the informed consent they give before undergoing treatment in Qatar. Methods: In June and August 2013, we conducted fifty-three semi-structured interviews with forty patients and thirteen family members at an Endoscopy Unit a Women's Hospital in Qatar. Interviews followed a guide involving a set of six, four and five questions related to the knowledge, attitudes and behaviors towards informed consent. Two previously trained students were present per interview. The interviews were transcribed and analyzed. The data collection continued until we achieved saturation of the primary themes. The latter are crucial and were used as a primary source for the questions of the survey which will be distributed among a wider population in the quantitative phase of our project that will be administered at the beginning of January 2014. Results: The results from the qualitative phase will be presented. We identified three themes in relation to participants' knowledge of signing informed consent forms: (1) that informed consent is meant to remove the hospital's liability and hold the patient responsible in case of adverse events that could happen during the procedure, (2) that informed consent is to inform patients of their procedure, side effects and benefits, and (3) that signing informed consent is a routine before undergoing any procedure. Regarding attitudes, we identified two contradictory adjectives to describe the information found in the current consent: (1) comprehensive, useful, acceptable and necessary versus (2) complicated, unnecessary, unclear and insufficient. After signing consent forms, patients mentioned three personal feelings: (1) responsible, satisfied and relieved, (2) scared, anxious and tense, and (3) felt nothing. Concerning the behavior questions, we identified three reactions when given the consent forms. Patients would: (1) directly sign it, (2) take time to read and ask questions before signing it and (3) pray a lot before signing it. Finally, concerning family involvement in the process of signing, we found three topics: (1) they did not participate at all, the family was not aware of the procedure, (2) they participated in signing instead of the patient and (3) they had a discussion with the family before signing, where the family was either supportive or not. We made sure to have a proper socio-demographic mix of interviewees, in terms of age, gender, nationality, education and perceived socioeconomic status. As for the quantitative part, we will expose preliminary results. Conclusion: The topics picked up by the qualitative phase will help us define possible culturally sensitive procedural strategies and in writing forms to obtain and document informed consent. The process of taking consent itself will be improved for a better doctor-patient communication, resulting in better patient care and a more satisfying patient and family experience.

Immigrant patients' and hospital staff's perspectives on a common cross-cultural encounter: Any trouble with Ethics?

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Background Health monitoring studies show significant disparities between the health status of the population with immigration background in Switzerland and the Swiss population. Associated to this, patient populations become ethnically, culturally and linguistically increasingly diverse – altogether 35.6% of outpatients up to 58% within a random sample are 'foreigners' at the University Hospital of Basel (UHBS) in 2011. At the same time, there is a high diversity on behalf of the hospital staff at the UHBS with 42.7% 'foreigners'. In this context little is known about ethical aspects within cross-cultural clinical encounters. Aim This research investigates how immigrant patients and hospital staff members experience their common communication and interaction with regard to possible different social and cultural backgrounds individually. In this context, the presented study explores ethical dimensions of critical factors in communication within cross-cultural clinical encounters in selected cases and their contribution for developing 'indication criteria' for clinical ethics support. Method The research is performed at two UHBS outpatient clinics. Overall, 32 outpatients with Albanian and Turkish immigration background are included. Semi-structured interviews are conducted with all actors being involved in the clinical encounter: patients, administrative staff, nursing staff, physicians and interpreters (if required) and complemented by participant observation. Data are analyzed by content analysis. Findings When triangulating perspectives on common communication, current results show that ethical aspects appear rather subtle than obvious. This is a challenge for good practice as they often remain unrevealed within consultations. To give an example: Both, a physician and his patient, experience their communication as difficult. The physician criticizes the patient's noncompliance with regard to his diabetes. He attributes the difficulties to language barriers, a limited intellectual ability as well as a fixation on own ideas about the appropriate therapeutic approach. In contrast, the patient mentions besides language barriers, having a hearing loss, which he did not disclose to the physician. As this simple example shows, cultural and language factors are not always central to a case and might actually hinder a more practical understanding - a hearing loss. Moreover, an interpretation that this was merely a communication problem would fall short of articulating the underlying ethical significance: a lack of trust of the patient and a lack of care on the side of the physician associated with an inclination towards judgmental assumptions. More types of situations will be presented for discussion. Potential candidates for indicating needs for ethics support are: disagreement about patient rights (e.g. not to follow directives), insufficient (mutual) respect / acceptance, issues of patient non-compliance and judgmental labeling (of the patient). Discussion The case material offers insight into situations below the threshold of 'perceiving ethical difficulties' or even 'evident ethical conflict'. Their analysis allows for the identification of needs for ethics support, i.e. improvement of therapeutic relation, e.g. through ethics education or consultation. We will put to discussion potential 'indication criteria' and suggest what kind of ethics support would fit which need.

SESSION 2C:
Clinical ethics: approaches, methods, evaluation

Evaluation of the feelings of patients and families after a stay in intensive care: Linguistic and medical analysis of letters addressed to the ICU

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Analysis of letters written by patients or their families following a stay in adult intensive care seemed to us to be a relevant approach to evaluating the feelings elicited by the stay, because the letters are written spontaneously. We evaluated correspondence received between 2002 and 2012: i.e., over 11 years, and submitted the letters to an analysis combining linguistic and medical questions. We found 323 letters, representing 5.14% of the 6286 patients (average age: 56.3 years) admitted to the ICU (23.6% of whom died): 231 letters came from family members (71.5%) and 92 from patients themselves (28.5%; 1.46% of admissions). Initially, the letters were posted in the staff break room, and then put away, although a certain number (impossible to specify) have been lost over the years. The letters are usually written on paper, cards, or postcards: they are rarely sent in the form of e-mail. Analysis brings out two major points: 1) the enunciative treatment of the writer (personal-pronoun count), how he addresses the staff ("you" "they," or by naming a member of the team); i.e. the enunciative modelization of the discourse; and 2) the themes of the letters, according to key words describing the subject's feelings about the ICU stay: anxiety, fear, hope; difficult moments: death, and the suffering of separation; expressions of thanks to individuals or the team; sometimes plans for the future or photographs of the reunited family. The content of the letters varies: some of the correspondence is conventional, formal, distant; other letters are personal, expressing the warmth of the relationships with ICU doctors or nurses, and the need to testify about the feelings aroused by the experience. The need to release these feelings is tangible in every letter, regardless of the author and/or the outcome of the stay. The existence of these letters shows that writing remains a classical means of communication, associated with the story of illness and the expression of narrative identity described by P. Ricoeur. In addition, over the same period, the hospital received 5 complaints, i.e. 0.79% of admissions. Two elements can be highlighted as a conclusion: first, the rarity of this type of linguistic/medical study on this sort of material, which presents the interest of having been spontaneously and freely written; second, its value to the staff. The study of the letters is personally gratifying, and they are also useful as a means of understanding the ICU emotional experience and improving the counseling services provided to patients and their family.

Strategies for starting and developing a clinical ethics unit associated with the healthcare partnership philosophy

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The clinical ethics unit at CHUM assumes a leading role in the field by offering various types of services: counseling and consultation, seminars and deliberation, mediation, training, etc., at every level of the organization (clinical teams, patient community, and organizational structures). Likewise, the clinical ethics unit assumes its duty as leader in promoting and developing ethics for the entire staff, administrators, doctors, interns, partners, volunteers, users, and their families. Activities are also integrated into each of the CHUM missions, which are providing care, teaching, research, and wellness promotion, as well as the evaluation of healthcare technologies and procedures. Inspired by the hub-and-spokes strategy (MacRae et al. 2005) and by the key skills developed by the American Society for Bioethics and Humanities (2009), we shall present ethics integration strategies at a Quebec teaching hospital. We will show how these strategies foster the development of better aptitudes and knowledge linked to ethical reflection and decision-making, while improving the quality of care and services for the public by engaging in a partnership with the user and his or her family. We will describe simple, innovative interventions that ensure the unit's integration, sustainability, and responsibility. Their goal is to contribute to the development of a culture of ethics and to promote communication, interdisciplinary cooperation, and a coherent policy in the best interest of the public and the instructors. As a conclusion, we will demonstrate how the activities of this unit influence the quality of life on the job, reducing staff turnover due to burnout and helping to relieve some of the caregivers' emotional pain. In the long term, these policies lead to improvements in care provided for patients, including better communication with them and their families.

Early Identification Gives Voice to Ethically Difficult Situations

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Often ethical issues are not addressed until they have escalated into ethical conflict. Research has demonstrated that nurses often delay or refrain from calling for an ethics consult, attributing concern for retribution and fears of harming their relationship with the patient. A tradition of reticence clearly calls for innovative tools that create opportunity for safe dialogue on ethical concerns. A new evidence-based Ethics Screening and Early Intervention Tool was pilot tested at two sites; with twenty-eight critical care and oncology nurses utilizing the tool a total of 100 times in their clinical practice over a period of three months. Assessing for key risk factors, nurses identified clinical situations with an increased likelihood for ethical conflicts. In those situations, nurses were asked to consider potential interventions and appraise their own perceived personal risk in carrying out those interventions. In both of the sites, nurses reported perceiving the least risk of negative consequences when discussing the issues with nursing colleagues or contacting chaplains. The three highest risks were: initiating an ethics consult, discussing with a physician, and exploring statements with patient, family. In follow-up focus groups, nurses emphasized the need for interdisciplinary conversations and opportunities to call for early ethics consultation – before matters heat up and evolve into interpersonal conflicts. Based upon those findings and informed physician input and expert review the tool has been revised, with the goal of strengthening the multidisciplinary interaction. In addition, the tool identifies key vulnerable populations as being high risk and may especially benefit from early identification. Early recognition may provide a clearer voice for those such as the elderly, homeless and unrepresented patients. An innovative, evidence based tool based upon nursing and physician clinical insights may lead the way to communicating about ethical concerns proactively and hence reduce conflict and improve the quality of care.

Communication denied: A pilot study of relational difficulties in the nursing profession

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The importance of communication in nursing care is referred to at length in the literature. The Pub Med search engine alone pulls up 588 articles on the subject. However, very few articles report on the refusal to communicate, or how a lack of communication can be instrumentalized, in a highly contentious situation, or a situation of avoidance. Goals: In order to establish a relevant analytical basis for the study, the number and intensity of times when the nurse does not communicate with the patient were evaluated. It is based on the observation of communication between nurses and patients in the internal medicine unit of an Italian hospital, over a 10-month period. An ethnographic method, with an observation log, was used. It is important to differentiate between a refusal and a failure to communicate, for in the latter case factors such as age, education, severity of the disease, time, and workload may be impediments. The denial of communication, on the other hand, contains a highly personal dimension, whereby the nurse always avoids contact with the patient, or constantly tries to reduce this contact to a minimum. Perception of the other is experienced in the first degree, with real difficulties in managing emotional and professional interaction. The nurse's attention to the needs of a hospitalized person is usurped by the routine duties and tasks incumbent on a staff person. Conclusions: Evading interaction may indicate the inner personal and professional fragility of the nurse. The refusal to communicate takes on meaning as a mirror, in which the nurse sees his or her flaws. Conversely, bringing such concepts out into the open makes treatment more effective and improves the quality of care, and can prevent the risk of professional burnout. The study is based on potential departure points, as a preliminary model for a more comprehensive study with a larger cross-section and more complex contexts.

Ethics Framework for Decision Making

Cathy COVINO, Nurse, Senior Director of Quality and Risk Management, Thunder Bay Regional Health Sciences Centre, Thunder Bay, Canada

Thunder Bay Regional Health Science Centre set out to develop an ethics framework for decision making. We believe it is integral to the overall moral commitment of the institution and has potential to enhance the ethical quality of interactions between patients, staff, clients and the community that it serves. We based it on our new mission, vision and values (MVV). The framework was created by three members of the Board and the co- chairs of the ethics team. This enabled the true living of our mission, vision and values to be part of decisions every day at every level of the organization. There is growing recognition of organizational ethics in healthcare delivery. Accreditation Canada includes ethics requirements in their standards. Standard 1.4 states: "The organization's leaders develop and implement an ethics framework to support ethical practice" (Accreditation Canada 2012) The framework was a series of questions to ensure decisions were focused on the Patient at all times. It supported our model of care, Patient and family centered care, as well. The decisions were always brought back to what mattered and what does it mean to the Patient. The framework can be a tool or algorithm that facilitates the ethical analysis of a number of decisions in a systemic manner. There were 4 high level questions that were placed on each agenda and briefing not template. The questions were referred to for decision making. If one of the questions were not answered sufficiently then reference to the larger framework would assist to further explore the decision. It should be noted that our framework was not designed to promote any numerical evaluation of responses, averaging, scoring or creating a threshold of acceptability. We feel that a global assessment of responses to all questions, performed separately for each decision option, gives the person or a group using it a good general idea of those options that are clearly inappropriate and those that may be ethically preferable. An ethics decision-making instrument should be evaluated to determine how it is used in the organization and how it meets the needs and expectations of users. However, we did not find in the published literature any such evaluation of frameworks for ethical decision making created for hospitals and similar institutions. An evaluation was completed by the Board and the Senior Management Council after a 6 month trial. The questions were around use of the questions, frequency, whether it was helpful and if they had any suggestions for improvement. The evaluation was favorable. No changes were made to the tool at this stage. The ethical framework is now being spread to the rest of the organization. The questions will be embedded in every agenda with education on use of the tool by the Bioethicist over the next 6 months.

Nurses' competencies for clinical ethics support services: who's afraid of ethics committees?

Bart CUSVELLER, Associate professor of Nursing ethics, Academy of Nursing, Christian University of Applied Sciences, Ede, Netherland

One of the ways to foster the patient's voice in providing good patient care is the advocacy of nurses representing the patient's perspective in organized forms of ethical deliberation and decision making. Examples are multi-disciplinary patient consultation, ethical rounds, or care-related ethics committees. Following the recent focus in nursing education on competency learning, the question may be raised which competencies nurses need to participate in pre-arranged forms of clinical ethics support services and give voice to the patient's interest. A competency profile may help health institutions, nursing education, and nurses themselves to determine how competent candidates for organized ethics consultations are and how to equip them for the role. An earlier study involving interviews with 52 nurses in ethics committees in The Netherlands resulted in a profile of qualities that nurses find essential to participate competently in ethics committees or other forms of organized moral deliberation and decision-making (Cusveller 2012). To corroborate the results of this qualitative study a quantitative study was designed. An online survey for nurses in ethics committees was developed on the basis of the competency profile and sent out to the subscribers of a Dutch professional journal for nurses with a bachelor degree. The result this survey aims at is a corroborated competency profile that may serve as the basis for an assessment tool to determine to what degree nurses do or do not in reality possess these competencies for participation in organized ethical deliberation and consultation. In this workshop the results of the survey and a first draft of the tool will be presented. An important question in the discussion will be if such a tool will enable nurses to give voice to the essence of their care, i.e. to foster the patient's well-being, in meetings for clinical ethics support. Reference: B. Cusveller (2012), Nurses serving on clinical ethics committees: A qualitative exploration of a competency profile, Nursing Ethics 19 (3):431-442.

Practical strategy to the implementation of ethical case reflection in a clinical ward

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Clinical ethics consultation is an integrated part of many health care systems in the Western world. In Denmark clinical ethics committees (CEC) is a rather new discipline, aiming at analyzing ethical dilemmas brought to the committee from the staff in the clinical wards. We have no tradition for structured ethical case reflection performed by the clinical staff within the wards. We represent a pediatric oncology ward in a large university hospital. When treating children with cancer and dealing with their parents and relatives in a multidisciplinary setting ethical, dilemmas are an inevitable part of our work. We hope that addressing these dilemmas will improve patient care and support the staff in their decisions. Here we present a practical strategy to the implementation of ethical case reflection in our ward. Methods Within the setting of the Nordic Society for Pediatric Hematology and Oncology (NOPHO) and the Nordic Society of Oncology Nurses (NOBOS) joint Working Group for Ethics we completed a workshop education as facilitators of moral case deliberation. In order to rehearse our skills as facilitators and evaluate the need and interest for ethical case reflection we created a rehearsal-group with five nurses from our department. None had formal education in ethics. We met six times once a month for two hours within working time. The nurses formulated their clinical case and what they felt was their ethical dilemma. At each session, one case was presented to the rehearsal group by the case owner. We, as the two facilitators, prepared and discussed the case and dilemma before the ethics session. The facilitators took turns leading the session and supporting the process. The sessions were evaluated by the rehearsal group. In summary, the sessions had brought a new important possibility to the department, a "new room for reflection". All felt that the structured method could be used to create important focus on ethical dilemmas and help reduce the burden to the individual experiencing a dilemma. All recommended the continuation of the sessions. We as facilitators gained valuable experience with our method, our group, future focus and our performance. The implementation of the ethics sessions is supported by the ward administration and is now a defined focus area for the coming year. The rather few hours spent on the ethics reflection sessions per month has made the continuation possible. We have thus scheduled open sessions for all pediatric oncology staff. Conclusion Our strategy of taking an education in a clinically oriented reflection method, creating a rehearsal group for practicing the method and attaining a positive environment for ethics reflection among participants and administrators has worked well in our department. We hope that this comprehensive strategy will inspire clinical staff with the desire to implement ethics reflection sessions within their clinical wards.

Program for health education beetween interpetation and understanding: the story's role

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In France, the number of patients suffering from chronic conditions is estimated to be around 15 million; i.e. nearly 20 % of the population. Some of them may be afflicted with several conditions at once. A condition is defined as "chronic" because it lasts for a long period of time and is likely to worsen gradually, often leading to disability and the threat of severe complications. The rate of compliance with medical advice and treatment for the condition is around 50% (1). In this context, France is introducing strong incentives to educating the patient with a chronic condition. How can we understand what is at play in non-compliance with recommendations and treatment, from the patient's viewpoint? We carried out a series of clinical interviews based on the open question "How do you deal with your asthmatic condition?" We interviewed both compliant and non-compliant adult asthmatics, all of whom were employed, over a two-year period. We deliberately chose not to interpret what they said, convinced that any attempt to explain their responses rationally would pathologize the patients. We opted for an analysis aimed at understanding the individual (2), at grasping the meaning the patient gave to his or her words. Based on a clinical case study, we illustrate the scope of the narrative. Over the two-year period, these narratives did attain some depth. They are explicit about "the dirt" of life that interfere with a mourning process for the healthy condition of the past, and lead to detachment in relation to the chronic condition. The patient is explicit about why he does not comply. For the speaker, learning in order to change cannot even be considered. His psychological and emotional energy is directed elsewhere. True, the patient's "chosen risk" (3) is respected. Contempt for daily life is liable to set in, if ethics is not a part of the encounter situation. Hence, education becomes a study of the patient's singularity, of a word that is uttered. In this context, the posture is above all clinical and ethical. It consists in granting the patient the ability to think, to develop his own thinking, to refuse a "ban on thinking." (4). Reaching compliance is then based on a trusting relationship: assistance in coping with oneself and developing one's abilities and perhaps even capabilities, in reference to Amartya Sen; to maintaining the relationship in the present, as a means of progressing slowly.

Moral case deliberation (MCD) –the role played by ethical principles, virtues and relational ethics

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Background In Moral-Case-Deliberation (MCD) a facilitator led group of health care workers, discuss ethical issues emerging from their experience with patient care. The purpose of MCD is to improve the quality of patient care, as well as to support health care workers in their daily practice. Ethical issues might be analyzed utilizing several different theoretical perspectives. Within biomedical ethics, the so-called "four-principles approach" has attained a dominant position globally. An alternative, but sometimes complementary approach, is that of virtue ethics, which focus on the character of the individual moral agent as well as on his or her values. Everyday ethics in the clinic seems to involve many psychosocial aspects that might be interpreted as relational ethics. There is a lack of knowledge about the content of the discussions that take place within MCD groups. Therefore this study aims to explore the ethical content of the dialogue with regard to ethical principles, virtues and relational ethics. Methods This is a qualitative descriptive study based on digitally recorded MCDs. Five Swedish hospitals with 12 different workplaces were included. The MCDs took place in hospital care with different specialties, mainly general internal medicine, dialysis and palliative care. Hospitals where the workers experienced need for ethical discussions, and which at the same time had access to local facilitators, were invited to participate in the study. The facilitators had undergone ethical training and represented the professions philosophers, chaplains and nurses. The groups gathered on a monthly basis on a total of eight occasions, and sessions lasted between 60 and 90 minutes. A total of 90 MCDs were digitally recorded. Criteria for exclusion were MCDs with thematic discussions that were not based on patient cases, and also MCDs that were not cross professional with both doctors and nurses attending. The final material for this study consisted of 30 digitally recorded MCDs. The MCDs were transcribed verbatim and the text was subjected to a qualitative content analysis. By using the software NVivo a deductive approach was used to extract which ethical principles were employed the most by the participants. Furthermore, the study examined how ethical virtues emerged as a part of the ethical conversation. The study also highlighted how everyday clinical work could be interpreted in terms of relational ethics. Results and Conclusions Analyses of the recorded MCDs are currently in progress. Thus, the results and conclusions will be represented at the conference. Knowledge about clinical ethics in everyday care is crucial for the development of support to health care workers when they confront challenging ethical issues. Insight of how ethical questions are discussed and handled by ordinary health care workers may also contribute to improved patient care.

What is a good facilitator of moral case deliberation and how to assess it?

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In Europe and specific in the Netherlands, more and more health care institutions implemented Moral Case Deliberation (MCD) as a form of clinical ethics support. A MCD is a methodical structured conversation among participants (mostly health care professionals) about a moral issue in a personal concrete case from one of the participants (Molewijk 2008; Dauwerse 2013). A MCD is facilitated by an ethicist or a trained health care professional (Plantinga et al, 2012). Theoretical viewpoints on both MCD and a good MCD are extensively described within the literature (Abma et al, 2009; Widdershoven&Molewijk, 2010; Weidema et al 2012; Dam van der et al 2011). However, the translation of these theoretical viewpoints to the concept of 'a good facilitator' has not been addressed explicitly, both in the literature as in the trainings of MCD facilitators. Whereas the USA developed a view and a concrete tool for determining the core competencies of clinical ethics consultants, in Europe there is hardly any literature about the conceptual clarification and practical examination of what it means to be 'a good facilitator of MCD'. Aim To clarify our theoretical viewpoints of 'a good MCD facilitator' and to develop a practical instrument in order to assess the quality of MCD facilitators for both facilitator trainings and regular MCD practices. Result On the bases of existing literature on theoretical viewpoints on MCD and on a good MCD, we developed an instrument in which the concept of a good MCD facilitator is operationalized into concrete and feasible behavioral terms. The instruments consists of a 4-paged form, consisting of four parts: 1) general information on and evaluation of the MCD; 2) open reflections in relationship to the facilitator's personal learning goals; 3) closed behavioral items connected to every step of the specific method for MCD (both dilemma method and Socratic Dialogue); and 4) general description of the attitude of the facilitator. The instrument can be used by the facilitator-trainee and the trainer for learning and assessing objectives. In this presentation we will present the content of the current instrument. The instrument mirrors our theoretical viewpoint on what it means to be a good MCD facilitator. We will describe the development of the instrument and the various ways we use the instrument in current training sessions for MCD facilitators. Based on the use of the instrument during the last year, we will share successes and pitfalls of this instrument and present some new challenges for assessing good MCD facilitators in the future. Discussion We conceive the developing process of the instrument not as a simple deductive translation of existing theories: it is a dialogical process and demands an on-going evaluation with the different stakeholders (e.g. trainees, trainers, trained facilitators, participants of MCD) both conceptually and practically. Although the instrument contains a normative view on the concept of a 'good facilitator' it should not be used as a golden standard since determining a good MCD facilitator depends on different contextual factors. This requires a careful and upright (integer) use of the instrument.

Which outcomes of Moral Case Deliberation do healthcare workers value? A questionnaire study in four European countries

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The overarching goal of Moral Case Deliberation (MCD) is to improve the quality of care for the patient, through a facilitator-led collective moral inquiry into a concrete difficult patient situation. The main participants are healthcare workers, but in some cases patients or their representatives also participate. There is no consensus regarding the importance of various outcomes of MCD and there is a lack of knowledge which outcomes of MCD healthcare professionals perceive as important, in various health care domains in various countries. The aim of the present study is to describe and compare European healthcare professionals' perceptions of the importance of different outcomes of Moral Case Deliberation. Gathering this knowledge will improve the efficient use of MCD and its contribution to the clinical practice. Methods: A questionnaire study with descriptive and comparative mixed methods design. About 500 healthcare workers from 30 workplaces in France, the Netherlands, Norway and Sweden, about to start series of MCDs, were approached. The partly validated instrument 'European Moral Case Deliberation Evaluation Instrument' (Euro-MCD) was distributed and filled in by the participants before a planned experience of MCD. The first qualitative part of the Euro-MCD entails an open question about which MCD outcomes they find important to reach. The second quantitative part comprises questions measuring the importance of 26 items representing various possible outcomes of MCD. The items represent six domains: Enhanced emotional support, Enhanced collaboration, Improved moral reflexivity, Improved moral attitude, Improvement on organizational level and Concrete results. The qualitative content analysis was conducted using the software NVivo. The quantitative data were analyzed through descriptive and comparative statistics (modes and percentages) using the software PASW Statistics. Results: Preliminary results from Sweden show unexpectedly that all items were graded as important, but items from the domains Enhanced emotional support and Enhanced collaboration were regarded as most important. About half of the open answers could not be categorized into the existing 26 items. These will be categorized together with the answers from the other three countries. Similarities and differences among health care professionals, their health care domains and the four countries will be presented at the conference. Conclusions: During the presentation, consequences for the development of Euro MCD as well as the MCD practice will be discussed. Furthermore, the next step in this European project on the evaluation of MCD will be presented.

Evaluation of an outpatient ethics consultation

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Background: For almost 30 years, clinical ethics committees have existed in Germany (Frewer, 2012). They advise patients and their relatives or physicians. These committees just work at hospitals. They are not responsible for nursing homes or for people who are cared for at home. That is the reason why there are some ideas for making outpatient ethics consultation in Germany. Two years ago, a group of three persons made an outpatient ethics consultation in Bavaria. At the moment, 17 persons are working for this committee. These members of the outpatient ethics consultation can be called by nursing homes, family doctors or relatives of people who live in a nursing home or who are cared for at home. The members of the outpatient ethics consultation advise these people, for example, with discontinuation or continuation of therapy, investigation of the suspected will or other relevant aspects. It is necessary to measure the success of these ethics consultations. Some guidelines for the evaluation of clinical ethics consultations just exist (Cambridge Quarterly of Healthcare Ethics, 18; 406-419). But there are no guidelines for the evaluation of outpatient ethics consultation. In the recent years, more and more outpatient ethics consultations were created in Germany. And so, it seems reasonable to examine the success and the benefit of such consultations. This is the reason why it is useful to question the members of the outpatient ethics consultation and to make some guidelines for an evaluation of outpatient ethics consultations. Methods: A qualitative study was conducted. It will be divided into two parts: First, there will be an explorative interview study in which three experts will be questioned. The questioned persons are the leaders of the outpatient ethics consultation. Second, there will also be an interview study with 17 members of the outpatient ethics consultation in Bavaria. Since September 2013, the explorative interview study has started. Up to now, two leaders was questioned. The third one will be questioned in November 2013. These are the issues of the interview: • Which are the differences between the clinical and the outpatient ethics consultation? • How many members work for the outpatient ethics consultation? Which kind of jobs do they have? Do they have a training for medical ethics advisor? • How many cases were processed during the last two years? Who can request the members of the outpatient ethics consultation? • How do they plan the consultation? (e.g. what models do they use? Which theories do they use? Which protocols?) • Why did they make an outpatient ethics consultation? • When did they start? What was important for the implementation of this consultation? The second part of the qualitative study will start in 2014. Results: There will be a third interview in November 2013. This interview is also important because the person who will be questioned ist one of the leaders of the outpatient ethics consultation. After this interview, the data will be evaluated with the software MAXQDA. The content analysis according to Mayring (Mayring, 2010) will be used. The first results are going to be expected in January 2014.

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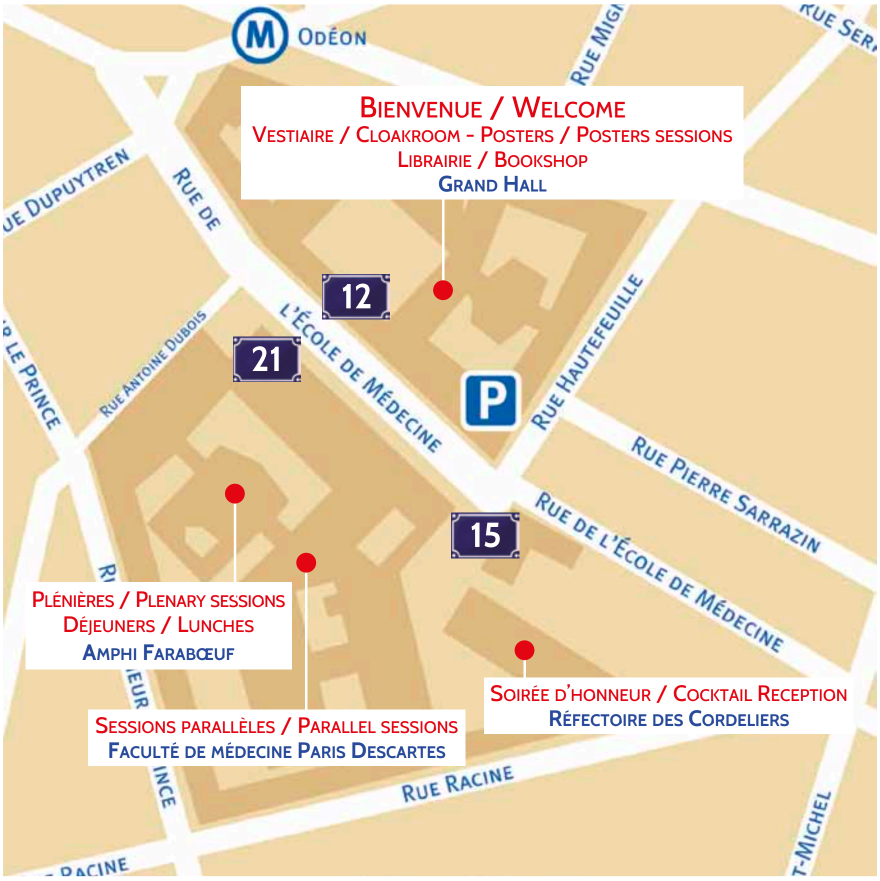

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