EACME Newsletter

European Association of Centres of Medical Ethics

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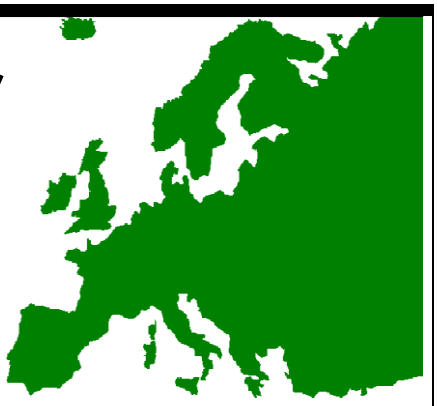

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EDITORIAL

Dear friends,

at this year's EACME conference in Leuven coming September we celebrate "30 years of Bioethics in Europe." EACME hence exists for 30 years already. On the one hand, this is a long time. On the other hand, biomedical ethics is still a very young discipline – if it can be even called a distinct discipline.

As regards myself, I am working in the field of biomedical ethics since 15 years. 15 years ago, when I just started with my thesis, it was not easy to explain my family and friends that I now specialize in "ethics". Most of them could not imagine what ethics could be about and with which topics I would have to deal with. Instead, they mixed it up with anthropology, psychology or theology. Today, I think this is different. Ethical issues are more in the focus of social awareness. At family gatherings possible risks of ZIKA-infections are discussed and nearly every week friends ask about pregnancy tests, genetic tests and / or reproductive health. Also, many of my friends and acquaintances are faced with the enormous challenges of their own parents' aging, including dementia etc. Ethical issues have become socially acceptable, more and more people are aware of ethical difficulties and ambiguities. Of course, this is also related to the increasing challenges or even dangers of globalization and is no longer restricted only to health and health care. The Daily News are full of actual or possible terrorist attacks, and these terrorist attacks question the basic values of our Western world. With this focus on values every news can be seen as an ethics lesson. Ethics is about values.

But what does this development mean for us ethicists? What do the next coming 30 years bring about for us that we all professionally work in ethics and who deal with value analyses all the time? I think it does not mean that we must be those to provide the solutions for all the problems and social tensions. Also, other professionals should not shift their ethical problems to us, e.g. in the healthcare system. Ethicists cannot make the decisions for doctors, just to name one example. I think it should however mean that we provide our expertise more to the public by communicating what we can offer as ethicists and what not. We should not hide at universities or behind research grants and projects. We need to work on the challenges of our time, while always keeping in mind not to get exploited when we realize that all the difficult ethical issues are shifted to us. However, I believe it is our responsibility to offer guidance in times where values are key to social development.

I'm excited and I'm looking forward to the next 30 years, but now please enjoy this newsletter,

yours

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THE CENTRE FOR BIOMEDICAL ETHICS AND LAW, KU LEUVEN

The Centre for Biomedical Ethics and Law (www.cbmer.be) was established in 1986 at the Faculty of Medicine of the KU Leuven. Hence, we are proud to announce the 30th anniversary of the CBMER that will be celebrated jointly with the 30th anniversary of EACME during the EACME Annual Conference “30 Years of European Bioethics” to be held in Leuven, September 8-10, 2016 (www.eacme2016.org).

The expertise of the Centre contains a wide variety of disciplines including ethics, law, philosophy, theology, social sciences and close relations are maintained with various disciplines in medicine and health care. The Centre for Biomedical Ethics and Law aims at conducting excellent research and education (www.masterbioethics.org) within the fields of medical ethics and medical law. The members of the Centre also contribute to the medical-ethical and legal dialogue on an interpersonal, institutional, and societal level. Research is organized along the lines of six interdisciplinary research lines.

Research line 1: Ethical, legal and social aspects of predictive medicine and genomics

The advances in genetic research lead to a clearer picture of the role of genetics in health and disease, which in turn drives the development of new diagnostic tools and treatments. However, rapid advances in the science of genetics and its applications have presented new and complex ethical, legal and policy issues for individuals and society. The overall goal of this research line is to examine ethical, legal and social aspects raised by genomic research and the integration of genetic technologies and information in a clinical setting and into public health. The aim of this research is to provide theoretical insight into the ethical and public policy implications of genetics; to conduct empirical social scientific research into the ethical and public policy implications of genetics; and to craft and inform genetic policy options and recommendations. As much as possible, this research will take place in an integrated context, which makes it possible to identify problem areas as soon as they manifest themselves in basic science, study them and develop solutions or appropriate ways of addressing them. This research line includes analysis of research topics such as public health genomics, direct-to-consumer genetic testing, biomarker testing, early testing for Alzheimer’s Disease and Autism, carrier screening programmes, neonatal screening programmes, biobanking, and implementation of sequencing technologies in healthcare settings (including issues such as return of individual results and incidental findings) and in international perspective.

Research line 2: Elderly care and end-of-life care. Ethical and legal approaches

As a consequence of population aging, ethical and legal issues concerning care for older people and end-of-life care will become more predominant. Moreover, the ethical issues linked to care for older people and end-of-life care have been debated on a societal level in most western countries. This resulted in some countries in legal initiatives (e.g. legislation on advance directives, euthanasia and assisted suicide). The overall goal of this research line is to examine ethical and legal issues raised by care for older people and end-of-life care in a clinical setting as well as on a societal level. The aim of this research is to provide a foundational care ethics approach – referring to concepts as vulnerability, care, and dignity – that enables us to properly analyse ethical problems in care for older people and end-of-life care; to conduct qualitative empirical research in order to get an in-depth insight into the ethically relevant characteristics of elderly care and end-of-life care practices; and to develop recommendations for ethical decision-making in clinical practice and on a societal level. Special attention will be given to the experiences of nurses and older adults who are involved in these ethically sensitive care

practices. This research will take place in an interdisciplinary context including philosophical, empirical methodological, and legal expertises. This research line includes ethical and legal analysis of research topics as sexuality and intimacy in dementia care, experiential approaches to ethics education in elderly care, e-health, telecare and robotics, advance directives, advance care planning, palliative sedation, euthanasia in specific patients groups (e.g. persons with dementia, persons tired of living, non-terminally ill psychiatric patients).

Research line 3: ethical and legal issues in organ & tissue donation and organ transplantation

Organ transplantation is the treatment of choice for many patients suffering from acute or chronic organ failure. However, the available supply of donor organs is insufficient to meet the growing demand. This has resulted in long waiting times for organ transplantation, putting the patient at an increased risk for mortality, morbidity and an inferior quality of life. Therefore, several strategies have been proposed in order to increase the number of organs for transplantation. The overall goal of this research line is to explore, analyze and evaluate the ethical and legal issues that are raised by strategies to increase organ donation. Specifically, we aim to provide theoretical insight into the ethical issues that are raised in the field of organ donation and transplantation, to conduct empirical research in order to assess the attitudes of various stakeholders, and to provide recommendations for ethical decision-making in organ & tissue donation and organ transplantation practice. The research will take place in an interdisciplinary context, which allows us to combine fundamental, empirical and legal approaches to organ & tissue donation and organ transplantation. This research line includes ethical and legal analysis of various research topics in the field of organ & tissue donation and organ transplantation, including post-mortem organ donation, living organ donation, ethical criteria for allocation of donor organs, trafficking and commercialism of organs for transplantation and pediatric organ donation and transplantation.

Research line 4: research ethics and ethics of research

Worldwide many scandals and cases of research misconduct have placed scientific integrity, responsible scientific conduct and scientific misconduct in the limelight. These issues are of concern for individual scientists, the international scientific community, the media and the general public. Besides within the field of biomedical sciences there is a permanent need for attention and research regarding ethical and legal responsibilities, rights and duties of researchers, clinicians in different kinds of (experimental) research on the one hand and of patients, society and participants in research on the other hand. This research line includes ethical and legal analysis of various research topics in the field of biomedical sciences: privacy, informed consent, right (not) to know, withdrawal, benefit sharing, research integrity, scientific misconduct, plagiarism, data management, etc.

Research line 5: legal regulation of the healthcare professions. European and comparative law

Developments in healthcare and health technology (ICT, e-health) as well as societal developments (chronic diseases, multimorbidity, population aging) are confronting the legal regulation of the healthcare professions constantly with new challenges. New functions, new professions and task shifting between existing professions require reconfiguring of the existing healthcare professions. New patient's rights are emerging such as the right to make an informed choice, the right to patient safety and the right to coordinated care. Another important evolution is the growing influence of European law on the legal regulation of the healthcare professions such as the directive on rights of patients in cross-border care and data protection regulation. This is resulting in ever more complex clusters of legal rules that govern the practice of delivery of healthcare and that need constant monitoring in a comparative way.

Research line 6: social and organizational ethics in healthcare

This research line considers the way in which ethical values are present in the practice of health care policy, organisation and management. As such, it takes the bioethical reflection, which for a long time has been predominantly focusing on issues in clinical ethics (i.e., the micro-ethical level) to the level of organizational (meso-ethical level) and social ethics (macro-ethical level). The aim of this research line is to inquire into the way in which ethical, philosophical and social theories can function as a guide for health care policy within society. We aim to reach theoretical insight into predominant ethical theories and theories of justice, to inquire into their implications for health care policy and organization on the macro, meso and micro-level, and to develop ethical guidelines for various topics in contemporary health care, such as cultural diversity in health care, commercialisation and privatization of health care, the moral identity of healthcare organizations, mission statement research, organizational support for ethical behaviour, and theories of justice regarding prenatal care, orphan drugs and rare diseases, the ethics of human enhancement, and the problem of **choices in health care**. This research takes place in an interdisciplinary context, combining the perspectives of philosophers,

economists, theologians, physicians, patients, pharmacologists, psychologists, lawyers, anthropologists, policy makers and health care managers. The applied methodology is a combination of fundamental ethical reflection with empirical research (qualitative design), as well as the regular use of Delphi-inspired consensus meeting methods.

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REPORT OF THE MEDICINE, MARKETS AND MORALS NETWORK

Medicine, Markets and Morals was a network grant funded by the Arts and Humanities Research Council (AHRC) in the UK. It was led by Lucy Frith (University of Liverpool) and Cam Donaldson and Rachel Baker (Glasgow Caledonian University). The Network aimed to consider the changing landscape of healthcare funding and organisation from an inter-disciplinary perspective, combing philosophical, ethical and health economics analysis.

The debate over healthcare funding in England is changing and the founding principles of the NHS (a free at the point of delivery, universal health service for all provided out of taxation) are being questioned. A House of Lords select committee was appointed in June 2016 to look at the long-term financial sustainability of the NHS. This new healthcare landscape necessitates renewed consideration of what type of health service we want and how healthcare should and can be funded in an age of austerity.

There are ongoing challenges for publicly-funded healthcare with respect to budgetary pressures and how to deal with scarcity. This basic problem leads to two main questions: what systems do we want to have; and, within these, how should resources be allocated. The Network explored this debate by bringing together philosophy and healthcare economics, two disciplines that seldom collaborate explicitly in this area, although both operate on the premise of 'scarcity' of resources and how that should be managed. Hence, healthcare funding is an issue that crosses disciplinary boundaries and insights from both ethics and health economics are invaluable in advancing these debates.

The debate over healthcare funding is one that affects all countries and is a deeply divisive issue (the debates over 'Obamacare' in the US have provoked intense controversy for example). Healthcare funding raises important philosophical and ethical questions which are, at root, about the role of the state in the provision of key resources - individual rights and state responsibilities – and consequent implications for the public-private mix in health and social care financing and provision.

There has been a substantial body of work done in philosophy on the issues raised by prioritisation in healthcare, but this literature has not engaged fully with the work done in health economics. Further, although there has been philosophical debate over, what is perceived as, the increasing commercialisation of healthcare in the US, there has been relatively little attention paid to the changes in healthcare in England in the philosophical and ethical literature. This Network will begin a multi-disciplinary dialogue to address these gaps in both theoretical and empirical research to inform public policy and future research needs in this area.

The Network explored two main areas:

1. Theoretical debates over resource allocation and priority setting in health and social care. The network explored the fundamental principles behind recent legislation in the UK on health and social care. With the increasing globalisation of health care these issues cut across national boundaries and the Network located these debates in a wider global context.
2. How the commissioning of services should be carried out in this new healthcare landscape ethically (fairly and equitably) within the given financial and policy constraints.

The Network also engaged with international debates to put the experiences of England and the devolved nations (Scotland and Wales) into a broader context. We invited contributors from countries that represent different models of healthcare provision (such as social health insurance systems, private insurance, out-of-pocket payments and dual models (taxation and social insurance) to give an overview of the challenges facing their health care systems and how we can learn from these. These contributions from the US, Canada, Australia, France, Norway and perspectives from developing world healthcare systems provided an international comparison of healthcare systems.

The Network held three meetings that were well attended and the papers and debates that followed were very stimulating.

Meeting One - Setting the agenda - International and disciplinary perspectives on health and social care financing was held in Birmingham and we had a range of speakers from different countries and disciplinary

perspectives to set out the central issues to be considered during the Network.

Meeting Two – Exploring the issues - resource allocation and commissioning was held in Glasgow and examined the theoretical issues that underlie these debates. Key areas were how to bring these perspectives together to inform the wider academic and policy debates and the role of the public in these priority setting processes (an important yet underexplored area).

Meeting Three – Bringing it all together - Reconfiguring public sector provision of health and social care – policy and practical implications was held in London and considered ways forward and next steps.

Now the programme of meetings is finished, the Network aims to continue bringing different disciplines and perspectives together to debate these key issues. We are planning an edited collection of papers from the Network and to hold some more meetings in 2017.

If you are interested in future activities please contact Lucy Frith to put on the mailing list (frith@liverpool.ac.uk). The full details of all the meetings, timetables, abstracts and PowerPoint presentations are on the Network website: https://www.liverpool.ac.uk/psychology-health-and-society/research/mmm/

MY EXPERIENCES IN DUTCH AND SWISS CLINICAL ETHICS SUPPORT

'Methodensicherheit' and Learning-by-doing

After working as a trainee at the Department of Medical Humanities of the Vrije Universiteit medisch centrum in Amsterdam for close to a year, I recently went to another EACME location at the Inselspital in Bern, Switzerland. In my 2-month internship there, I wanted to gain insight into possible cultural differences in implementing clinical ethics support (CES). I succeeded. My internship left me torn between two worlds: Swiss Methodensicherheit (methodological security) and the Dutch learning-by-doing approach.

Both in Amsterdam and Bern I participated in CES, particularly in moral case deliberation (MCD). This is a form of CES developed in the Netherlands that enables health-care professionals to hold structural dialogues and tackle moral dilemmas on the ward. The method is based on hermeneutic philosophy. It follows the idea that although general concepts, and ethical theory can be elucidating and inspiring, it is only the contextual meaning of concepts and arguments that are truly valuable. While I had participated in and witnessed many MCDs in Amsterdam, I joined an MCD facilitator training in Bern. It was this training programme that showed me some distinct cultural differences between the Netherlands and Switzerland. I would like to share one of these subjective observations in this opinion piece.

One of the things that always fascinated me about working in clinical ethics in Amsterdam is, what I will call: the learning-by-doing mentality. The idea that skills are gained and perfected through practice, is one that is also immanent in the Dutch MCD method as such, seeing as it focuses more on personal experiences than abstract, theoretical thought. Through talking to my colleagues and others who were following the MCD training programme, I soon learned that many health-care professionals who partake in MCD trainings desire to train and practice the method in a group or in the field. Although they are interested in theoretical background information and often ask for clearer definitions of 'norms' and 'values' during the training sessions, many also want to test the functionality of the CES technique hands-on. They want to learn-by-doing.

My experience with the Swiss approach, however, was slightly different. Before, during and after the MCD training programme I participated in, I heard many demands for more Methodensicherheit. People wanted to read more literature, get acquainted with those philosophical streams underlying the method and gain even more in-depth theoretical knowledge than the Dutch. "I can and will not implement a method, if I am not 100% secure with the underlying theory", was something I heard regularly. The wish for more conceptual understanding was echoed by many and has been a consistent demand from previous trainings of this kind in Bern, as I heard from a colleague. Rather than learning the method through practice, many Swiss health-care professionals wanted to reach full methodological and theoretical understanding before they could even think about implementation. They wanted to reach full Methodensicherheit, while their Dutch colleagues where more open to learning-by-doing. In Switzerland, I truly realised that the same CES technique faces different challenges when implemented in different cultural contexts.

Of course this is a personal experience, and might not be fully representative. Still, my traineeships in both settings made me wonder and want to share three questions: How much practical experience and theoretical philosophical know-how is required when implementing clinical ethics in the first place? How does this differ from country to country? Can cultural differences, like the wish for Methodensicherheit or

learning-by-doing, be fully accounted for in one CES training approach?

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ANCRAGE DU CONSEIL ÉTHIQUE DANS LE QUOTIDIEN CLINIQUE

L'Académie suisse des sciences médicales a émis en 2012 des recommandations sur le soutien éthique en médecine. Elle organisait le 21 avril 2016 à Berne un symposium auquel ont participé une centaine de professionnels, faisant le point sur les enjeux et les perspectives d'avenir. D'abord, il convient de relever que (comme toujours pourrait-on dire) il n'y a pas une manière standard, qui serait la seule bonne, d'implanter le conseil éthique dans un hôpital, un établissement pour personnes âgées dépendantes ou la pratique ambulatoire. La chargée d'éthique d'une clinique de Lucerne a dit que « l'essentiel n'est pas comment une situation difficile est analysée, mais qu'elle le soit ». La formule pourra surprendre mais le fait est que des chemins différents sont possibles. La première condition est que les responsables organisationnels/exécutifs accordent à cette fonction la place nécessaire – et des moyens qui permettent de l'assumer. Un orateur a relevé qu'un scandale peut être le facteur déclenchant d'une préoccupation éthique institutionnelle, mais il est évidemment préférable de ne pas attendre une telle occurrence.

La possible professionnalisation du conseil éthique a été évoquée. En Suisse et à court terme, il ne paraît pas que la solution puisse être recherchée dans une exigence de formation unique aux conditions rigides. En effet, la fonction est assumée par des personnes dont la formation de base peut être aussi bien la médecine, une profession soignante, la philosophie ou la psychologie, voire le droit. Cela étant, elles doivent avoir bénéficié d'une expérience pertinente, aux plans théorique comme pratique, et démontré leur engagement dans ce domaine - y compris un talent pour la réflexion et le débat interdisciplinaires.

Le prof. Bert Molewijk, d'Amsterdam, a présenté la « moral case deliberation », approche contextuelle et pragmatique de l'éthique clinique, ancrée dans l'expérience des professionnels qui apportent leurs interrogations dans un dialogue structuré facilité par un éthicien [(1)]. « Le soutien éthique clinique n'est pas une fin en soi » a-t-il dit, allusion à ce qu'il s'agit d'un rôle/prestation de service aux praticiens qui sont au front. Il a souligné l'importance de stimuler, chez ceux qui sollicitent une appréciation, un sentiment de co-propriété et de co-responsabilité dans la démarche éthique et les conclusions qu'on en tire. Rappelons que les commissions ou consultants en éthique sont là pour délibérer des valeurs, droits et intérêts en jeu dans la situation soumise et pour esquisser les avenues/actions possibles (cas échéant la « moins mauvaise » avenue). Notamment aussi pour discuter de désaccords apparus dans l'équipe. Ce faisant, ils formulent des analyses ou recommandations mais, en règle générale, la responsabilité des décisions pratiques, au lit du malade, reste avec le médecin et l'équipe soignante. En bref : on ne saurait imposer des positions éthiques, on en débat et on s'efforce d'arriver à un consensus.

La responsable de l'unité d'éthique d'un hôpital universitaire a noté que ce sont plus souvent les chefs de service qui soumettent une situation complexe plutôt que des collègues juniors. Y aurait-il chez ces derniers la crainte qu'une demande de leur part soit vue comme un signe d'insuffisance ? Alors que, bien souvent, dire « Je ne sais pas » doit être vu comme une forme de responsabilité, de courage même. Et il faut plus de courage encore pour attirer l'attention d'un chef sur des aspects éthiquement discutables dans son propre service… Une personne oeuvrant dans un cadre déontologique plutôt conservateur a relevé que les désaccords entre les médecins et un corps infirmier plus ouvert étaient fréquents. Ellen Fox, spécialiste américaine de l'Université Clarkson, a parlé de « psychological safety » : pour des débats fructueux, la sécurité psychologique, en d'autres termes la confiance au sein de l'équipe est un facteur majeur, nourri par une atmosphère d'écoute et de respect mutuel. L'objectif est l'émergence d'une véritable culture éthique partagée dans les prestations de soins. Je signale à ce propos la parution récente d'un utile ouvrage issu de Suisse francophone [(2)].

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1.Molewijk B., Abma T., Stolper M. Widdershoven G. Teaching ethics in the clinic. The theory and practice of moral case deliberation. Journal Med. Ethics 2008, 34, 120-124.

2.Corbaz P., Quinche F. Ethiques pour les soins à domicile. Genève : Éditions Médecine et Hygiène, 2015.

OLDER PERSONS AND OPTIONS FOR ADVANCE DIRECTIVES

This short contribution introduced the option of advance directive in future healthcare planning for older people. An advance directive is an instruction given by a competent person about withdrawing or withholding medical treatment when the person becomes incompetent to consent to or refuse treatment in the future.

Advance directives were advocated as valuable tools to protect the right to make decisions[1] although there were critiques about its effectiveness when the person became incompetent.[2] There is a growing recognition of advance directives and it is recognised in the common law jurisdiction. For example; the Mental Capacity Act 2005 applicable in England and Wales gives advance decisions refusing treatment a legally binding status. Australia and Singapore have also granted specific ADs legally binding status in their respective statutes.[3] Despite its value and the legal provisions to the effect, the awareness of its utility and subsequent uptake within the older population remains low, particularly in developing countries. Within England and Wales, only specific advance directives have legal binding status, while other preference statements are only persuasive. With this background in mind, this short contribution seeks to explore and advocate the use of advance directives as applicable to the older population.

An advance directive that was made when the person was mentally capacitated, acted voluntarily and with an understanding of the nature and consequences of the refusal would be upheld. As such, an advance directive encompasses the common law principles of rights of bodily integrity and of autonomy of people who are temporarily or permanently incapacitated by accident, disease or some other events. Common law cases on advance directives that have developed prior to the introduction of statutes governing advance directives reflect the principle of respect for individual autonomy.

The topic of advance directive is highly relevant for older people. Given the growing and greying population across the world, it is timely to examine the care of older persons in terms of planning for their future healthcare and ways of respecting and implementing their preferred treatment in accordance with their values. As ageing and health are interdependent, rapid population ageing will impact upon the healthcare provision in both developed and developing countries. Many countries have progressively witnessed an increase in ageing population, in tandem with medical advancements in the form of life-prolonging or life-sustaining intervention. For example, older people may be more likely to suffer from the effects of dementia, or progressive illness. Healthy, older people thinking about planning for the future can also benefit from the process of expressing their wishes in advance directives in anticipation of future illness.

The process of creating advance directives can be carried out as part of the primary healthcare provision. It has the potential to improve outcome on patient care, while respecting the exercise of autonomy by the elderly. Additionally, incorporating advance care planning into elder care framework enhances elderly health, facilitate better distribution of resources and reduce long term care. Making advance directives in advance care planning among the elderly is not confined to planning death, rather, it promotes the initiation of conversations pertaining to aspects of daily life and future medical care, and which is valuable in promoting overall elderly health in the latter stage of life. Good elderly health will impact upon the socio-economic well being of the country in terms of optimising the provision of health resources to the elderly. Planning in advance facilitates healthy ageing, resulting in treatment decisions to be made without resorting to unnecessary life-prolonging treatment.

As indicated above, an advance directive is invaluable in demonstrating the person's preferences. In creating advance directives, older persons would have the opportunity to receive support in the form of professional help from doctors as well as in the presence of family or trusted support person, if they wish. Set within a professional environment, the older person can express his or her preferences for treatment, or to clarify their wishes. Similarly, this would provide the chance to express any concerns or

[1] L. Kutner. The Living Will: Coping with the Historical Event of Death. Baylor L Rev 1975; 27: 39–53: 27, 39; M.J. Silveira, S.Y. Kim & K.M. Langa. Advance directives and outcomes of surrogate decision-making before death. N Engl J Med 2010; 362: 1211–1218 (An investigative study which supported the continued use of advance directives in elderly patients who had prepared advance directives received care that was strongly associated with their preferences); N.L. Cantor. Advance Directive Instruments for End-Of-Life and Health Care Decision Making: Making Advance Directives Meaningful. Psych Pub Pol and L 1998; 4: 629–652.

[2] Some examples are A. Fagerlin & C. Schneider. Enough: The Failure of the Living Will Hastings Center Report 2004; 34: 30–42; H.S. Perkins. Controlling Death: The False Promise of Advance Directives. Annals of Intern. Med. 2007; 147: 51–57; C.J. Ryan. Betting your life: an argument against certain advance directives. JME 1996; 22: 95–99.

[3] Advance Medical Directives Act 1996 (Sg), Mental Capacity Act 2005 (UK), Guardianship and Administration Act 1990 (WA); Medical Treatment Act 1994 (ACT); Guardianship and Administration Act 2000 and Powers of Attorney Act 1998 (Qld); Consent to Medical Treatment and Palliative Care Act 1995 (SA), Advance Care Directives Act 2013 (SA), Medical Treatment Act 1988 (Vic), Advance Personal Planning Act 2013 (NT).

doubts about treatment, the exchange of information to come to a treatment decision or raise any reservations in end-of-life care options. Such clear communication is vital, because it enables the creation of advance directives which are more likely to be accepted as valid compared with an advance directive that is created in isolation.

It is significant to understand that an advance directive is not an end in itself. It is a useful instrument to start a conversation about future medical plan and an advance directive provides an avenue for them to think about and communicate their wishes according to their values or beliefs. The option of creating advance directive for older persons to govern their future medical treatment is ethically defensible as an example of exercising their autonomy through expressions of choices about future treatment. Their valid preferences ought to be respected when the anticipated time arrives and they become unable to take any healthcare decisions.

A future care planning process provides a valuable opportunity for older people to discuss and create advance directives that enable them to express their preferences for future care treatment. These advance directives, in turn, facilitate healthcare professionals in implementing the preferences of older people, and contributing to care and treatment that closely resembles the preferred treatment.

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THE CASE OF HOME BIRTH IN HUNGARY

Keywords:

responsibility, informed consent, medical harm, obstetric care, home birth, Hungary, decision-making

Decisions around birth are influenced by many factors, some of these factors do not necessarily serve the best insterests of mothers or their babies.
Information provided to childbearing mothers regarding treatment options and choices is therefore often distorted and misleading. To achieve the highest standard of obstetric care, evidence based scientific information should be given to mothers. The paper discusses the case of home birth in Hungary to demonstrate elements of avoidable medical harm caused by non-medical factors including professional prestige and financial inducement.

Various issues related to child delivery were frequently discussed in mass media and in professional conferences in the recent years in Hungary. Demographic problems, the exodus of obstetricians, increasing rate of Caesarian sections, as well as issues of money of gratitude and home birth do provoke a lot of emotions since these questions influence people on personal and political level as well. Apart from questions related to the place of birth and money of gratitude, the quality of birth process is hardly discussed. Many believe that the safety of the newborn baby and her mother is the most important factor in child delivery: if the baby and her mother are fine after the delivery all other issues become of secondary importance. Although issues of safety are no doubt very important, the way the baby is born, the way how the mother is treated during this process, the way the mother experiences the whole process may have long term effect on the well-being of the baby and her mother. Others argue that we need to avoid the overdramatization of delivery, all of us were born somehow, and yet here we are with our hopefully happy life. This argument is also rudimentary: the effects if physical and psychological traumatization of the mother, the avoidable medical intervention are not taken into consideration.
The importance of these considerations is reflected by the fact that around 9 % of delivering mothers can be considered as seriously traumatised after giving birth. (http://www.postpartum.net/learn-more/postpartum-post-traumatic-stress-disorder/ *Retrieved 19. November 2015*)

Traumas around delivery may have a deep impact among others on the bonding, on the postpartum mood of the mother, on the sexual relationship of the mother and her partner, and on the willingness opf the mother to have children after the delivery. Many mothers confess that they do not plan to have more children because they would not like to repeat the trauma of their delivery. (BUDA Béla: A szülés Janus-arcai. Komplementer Medicina. XI. évf. 2007/1. http://www.module.hu/index.php?option=com_content&view=article&id=216 *Retrieved 19. November 2015*)

Even the health of the newborn baby can be affected by superfluous or sometimes even harmful interventions, moreover, it is well known that Cesarean sections without medical indication worsen the health outcomes of newborn babies. Since it is a major surgery with its complication for mothers, therefore if it is done without medical indication, there is no benefit only harm for mothers: as with any surgery, Caesarean sections are associated with short and long term risk which can extend many years beyond the current delivery and affect the health of the woman, her child, and future pregnancies.

WHO Statement on Caesarean Section Rates

http://apps.who.int/iris/bitstream/10665/161442/1/WHO_RHR_15.02_eng.pdf *2015. Retrieved 19. November 2015*

For a better understanding of the situation of decision making around childbirth some elements of the Hungarian and international practice of home birth will be analysed here. The analysis of home birth illustrate several issues about responsibility, respect, medicalisation and medical harm.

The practice of modern age home birth has a history of almost three decades in Hungary with more than 3,000 children born at home. This number can be considered high enough to draw some generalizable conclusion. It is well known that home birth is an accepted practicein industrialized countries.

There is a war in obstetrics around home birth in Hungary. The objective of this war is to maintain professional dominance and to protect the financial income of obstetricians working in hospitals at the price of women's safety and scientific truth. It would be unfair and unjust to condemn the obstetric profession as such; however, the vast majority of official professional statements and expert opinions related to home birth do confirm an intention to eliminate the practice and practitioners of home birth. The existence of home births is a threat to the hegemony of obstetric profession for different reasons.
The home birth movement demonstrated that midwives can safely and effectively manage deliveries of healthy women, thus making the presence of qualified obstetricians unnecessary in the majority of cases.
(Szebik, I. Otthon vagy biztonságban – otthon és biztonságban. Credo 2011/4.)
(Szebik, I. Ki marad a kamarában? LAM 2002;12(3):172–180.)

Moreover, the professional activities of midwives brought into question the necessity and benefit of many practices routinely administered at hospital births (episiotomy, induced labour, spinal position, etc.).
One manifestation of this war in Hungary is the criminal prosecution of the midwives who attend home birth. Although the government of Hungary issued a governmental decree regulating home birth, as long as criminal prosecution is a standard practice to judge the professional activity of midwives in cases of bad outcome, it is hard to believe that there will be peace around home birth.
In the course of the recent criminal trial of Ágnes Geréb obstetrician/midwife and other home birth midwives, we witnessed that,in their testimony, expert obstetricians falsified scientific evidence and came to unfounded conclusions regarding cases of homebirth.

The objectivity of obstetricians who testified as experts in cases of home birth is questioned for several reasons:

1. The practice of home birth offers an alternative approach in pregnancy care. This approach is not arbitrary or idiosyncratic, but is usually based on scientific evidence. Many ineffective or even harmful practices, however, that are routinely administered at the majority of hospital deliveries are not applied at home birth, and their absence can be seen as an implicit criticism of current Hungarian hospital protocols.

(World Health Organization, Maternal and Newborn Health/Safe Motherhood Unit: Care in normal birth: a practical guide)
http://apps.who.int/iris/bitstream/10665/63167/1/WHO_FRH_MSM_96.24.pdf *Retrieved 19. November 2015*

Although home birth services are not covered by the National Health Insurance Fund, the practice of home birth offered a fair and equitable financial model for pregnant women. During pregnancy, women in Hungary are required to attend visits at private clinics if they want to avoid embarrassingly long waiting time. These private visits are not covered by the National Health Insurance Fund. Moreover, if a pregnant woman prefers to deliver with an obstetrician she selects, for this she usually has to pay out of her own pocket (this is a form of informal payment or tipping). These payments serve as a major source of income for obstetricians. The amount a pregnant woman is required to pay for regular pregnancy care and for hospital delivery is at least three to four times higher than the amount she is expected to pay for home birth. Again, the practice of home birth in Hungary not only offers a fair and transparent financial model for pregnancy care, but implicitly criticizes corrupt practices often present in hospital pregnancy care.

Planned home birth has been shown to be a safe and convenient option for healthy women in industrialized countries, when professional birth attendants are present.
(Olsen, O. Meta-analysis of the safety of home birth. Birth 1997 Mar; 24(1):4-13 .)

In the majority of cases, these professionals are midwives. In Hungary, hospital births are almost exclusively attended by obstetricians, and midwives have an inferior role. The mere existence of home birth demonstrates that obstetricians are not routinely needed for healthy deliveries, a realization that threatens to diminish the prestige of male-dominant obstetric care in Hungary. This is perceived by many obstetricians as a threat to their income.

The obstetrician called to testify as expert witnesses during the criminal trials unanimously expressed their

disapproval of home birth because of its alleged increased risk, compared to hospital birth. This unfounded bottom-line dominated their statements, opinions and conclusions. An example to illustrate this point:

- Obstetrician-midwife Dr. Ágnes Geréb was condemned because of professional misconduct for not incubating a newborn baby who lacked breathing. Instead, she applied the standard reanimation technique with a mask. This is a double standard, since health care professionals in hospital delivery units do not incubate newborn babies before resuscitation either. In fact, courses on resuscitation teach that reanimation with mask is an efficient technique under standard circumstances. Professionals working at perinatal intensive care units and in perinatal ambulance cars certainly have sufficient skills to incubate babies, but this is not a requirement in standard hospital wards.

As we have seen the situation if home birth raises some important ethical issues. The ignorance of scientific evidence violates patients' rights by causing avoidable harm to pregnant women and makes informed choice of mothers impossible. Furthermore, the professional integrity of health care providers is disrespected.
Decisions around birth are influenced by many factors, some of these factors do not necessarily serve the best interests of mothers or their babies.
Information provided to childbearing mothers regarding treatment options and choices is therefore often distorted and misleading. To achieve the highest standard of obstetric care, evidence based scientific information should be given to mothers and scientific evidence should be respected by health care professionals.

This paper is an extended and edited version of the oral presentation: Szebik, I. Justice and Home Birth in Hungary: Show trials in the 21st century. Human Rights in Childbirth Conference: Bynkers Hoek Institute, Hague, Hollandia, 2012.05.31-06.01. (2012)

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HANS-JOACHIM SCHWAGER-PRIZE FOR CLINICAL ETHICS FOR 2016 GOES TO BULGARIA

On 20-th of May at the opening ceremony of the 12-th International Conference on Clinical Ethics and Consultation the Hans-Joachim Schwager-Prize for Clinical Ethics for 2016 was presented to Silviya Aleksandrova-Yankulovska. The Hans Joachim Schwager Award aims at individuals or groups, who perform innovative or pioneer work in clinical ethics. Its major goal is to support practitioners who have successfully implemented ethical consultation in healthcare facilities[4].

The prize goes to a scientist from Eastern Europe for the first time, which is considered a very significant achievement for the development of the field of clinical ethics. In 2013 Hans-Joachim Schwager-Prize was presented to Hugo Gold from Children's Bioethics Center, Melbourn, Australia and in 2014 – to Timo Sauer from Netzwerk Ethik in the Altenhilfe Frankfurt, Germany. Professor Aleksandrova-Yankulovska and the Section of Medical Ethics of Medical University of Pleven, Bulgaria are among the newest members of EACME. Their application was approved in April 2016.

The wining project is named "Application of adapted METAP methodology for clinical ethics consultation in Bulgaria**"** and took place in 6 clinical units (neonatology, pediatric ward, regional specialized cardiological hospital, two medical centers and a comprehensive oncology center) in the country in the period May 2013 – December 2014.

The clinical units were chosen on the basis of the following criteria:

- ✓ Representation of different clinical specialties;
- ✓ Representation of in-patient and out-patient units;
- ✓ Availability of at least one team member with bioethics training or expertise in psychology.

Upon the end of the study period the following **participants** were involved in the programme:

- Heads of clinical units – 4 people;
- Treating physicians – 20 people;
- Consulting physicians of 7 specialties (neurosurgery, chemotherapy, cardiology, neurology, pulmonology, anesthesiology, neonatology) – 14 people;

[4] Hans Joachim Schwager Award information available on ICCEC website: http://clinical-ethics.org/Flyer_HaJSAw_2016.pdf

- Other consultants – surdopedagogist, embryologist – 3 people;
- Psychologist – 3 people;
- Nurses and midwives – 9 people;
- Patients – 61, of them 23 were present at the ethics meetings;
- Patients' relatives (spouses, parents, siblings, children) – 57 people;
- Other participants (other patients, social services representative, interpreter) – 7 people.

Several **specific instruments** were developed in relation to the implementation of the methodology for CEC[5]: validated translated protocol of ethics meetings, validated translated information check-list, adapted informational brochure, PowerPoint presentation of the methodology for the preliminary meetings with the personnel, questionnaire for interview with the personnel at the preliminary meetings, questionnaire for extraction and analysis of information of ethics meetings, and feedback self-administered questionnaire.

In total 69 meetings took place in the chosen wards (***table 1***). Thirty two of the meetings (46,4%) took place in the comprehensive oncological center.

Table 1 – Ethics meetings by chosen wards

№	Ward	Ethics meetings	
		n	%
1.	Cardiological hospital – Veliko Tarnovo	10	14,5
2.	Comprehensive oncological ward - Vratsa	32	46,4
3.	Center for reproductive medicine - Varna	2	2,9
4.	Neonatology - Pleven	4	5,8
5.	Pediatrics - Pleven	10	14,5
6.	Medical center "Galileo" – Pleven*	11	15,9
Total		**69**	**100,0**

** Out-patient center for otorhinolaryngology and neurology*

General characteristics of the ethics meetings included:

- ✓ Majority of the meetings were organised for first time (87,0%).
- ✓ Total number of participants in ethics meetings was 286. The majority of the meetings were hold with the participation of 4 people (31 meetings, 44,9%).
- ✓ In all meetings a physician was involved and in some cases also a consulting physician.
- ✓ The patient was directly involved in 25 meetings.
- ✓ The average duration of ethics meetings was 36 minutes.

The reasons to organise the ethics meetings were systematized in 9 categories (***fig.2).*** In 22 meetings (31,9%) the reasons for the meetings was related to the choice of treatment among available alternatives with non-medical factors involved. Second most common reason to organise ethics meetings was "accusations on the side of the patient/relatives/personnel in inadequate attitude or treatment" (16 meetings, 23,2%). These were different conflicts including rude and humiliating behavior on the side of the patient and relatives.

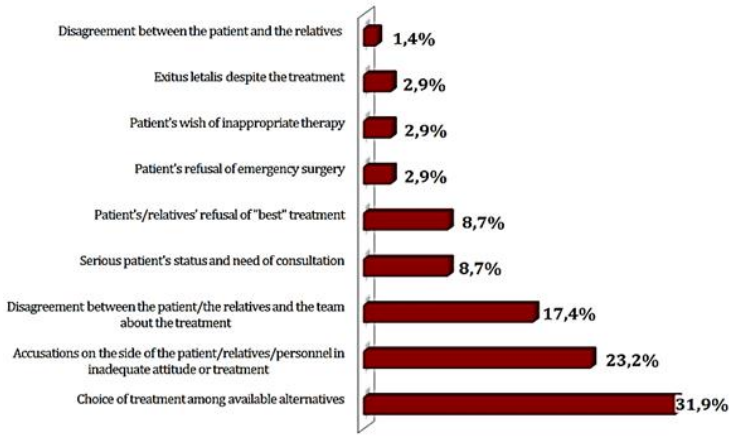


Fig. 2 – Reasons to organise ethics meetings

The outcome of ethics meetings was evaluated in accordance with the criteria suggested by Pfafflin, Kobert и Reiter-Theil[6] through originally developed feedback self-administered questionnaire. Feedback self-administered questionnaires were filled in by 68,81% of the participants. Of them 39% were physicians, 22% were psychologists, 15,9% nurses and midwives, and 11,3% patients. However, we have to stress upon the positive fact that in practice, we managed to collect all patients opinions: out of 23 patients, who participated directly in ethics meetings, 22 (95,7%) filled in feedback questionnaires.

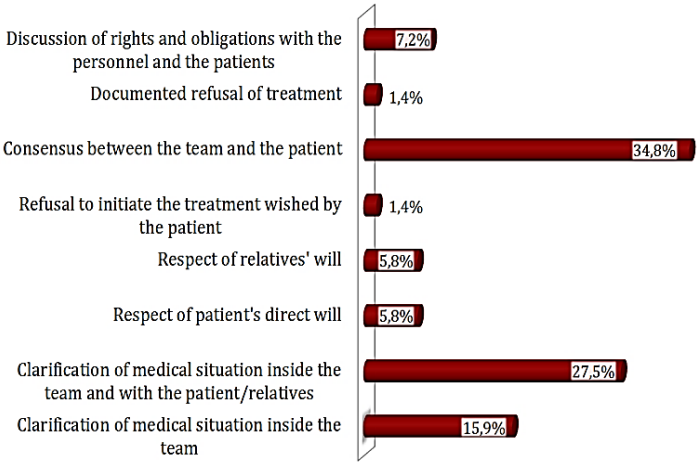
In 24 of the meetings (34,8%) consensus was achieved between the team and the patient (fig.3). In 19 meetings (27,5%) the medical situation was clarified inside the team and with the patient/relatives and in 15,9% - only inside the team.

[5] Reiter-Theil S, Mertz M, Schürmann J et al (2011) Evidence – Competence – Discourse. The Theoretical Framework of the Multi-centre Clinical Ethics Support Project METAP. Bioethics 25(7): 403-412.
Albisser H, Mertz M, Meyer-Zehnder B, Reiter-Theil S (2012) Klinische Ethik METAP – Leitlinie für Entscheidungen am Krankenbett. (Clinical Ethics METAP – Guideline for Decisions at the Bedside). Springer, Heidelberg, Berlin, New York

[6] Pfafflin, M., K. Kobert, S. Reiter-Theil. Evaluating Clinical Ethics Consultation: A European Perspective. - Cambridge Quarterly of Healthcare Ethics, 2009, vol.1, pp. 406-419.

Satisfaction with the meeting was expressed by 171 (87,7%) of the participants, who filled in feedback questionnaires.

Fig. 3 - Results of ethics meetings



The participants formulated several ***most significant benefits of the meetings***: better clarification of the problem (26,4%), better communication in the team (20,8%), confidence in the rightness of the decision (18,6%), clarification of legal and ethical aspects of the problem (17,5%), better understanding of patient's preferences (15,9%).

Since there was no literature on clinical ethics consultation in Bulgaria at the time of the initiation of the above described methodology, the author published ***monography "Clinical ethics consultation"*** [7] in 2015. The instruments of the adapted METAP methodology are included in the book thus being available for application in different settings by clinicians. Forty pages of analysed by the author cases present additional useful material for physicians who would try to apply the methodology in their practice. The book can be used also as a reference material in education of health professionals on under- and postgraduate level.

ACKNOWLEDGEMENTS
Special gratitude to Prof. Stella Reiter-Theil for encouraging the start of this attempt to introduce clinical ethics consultation in Bulgaria, the provision of knowledge and materials of the original METAP project and all advises given on the way of project implementation.

[7] Available official information in Internet at: http://philosophy-bioethics.eu/polezno/materiali/klinitchna-etitchna-konsultatsiya-silviya-aleksandrova-yankulovska/ and https://stenobooks.com/product/2535/klinichna-etichna-konsultatsia.html

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