

XV Annual Conference

International Society for Clinical Bioethics



International Society for Clinical Bioethics
XV Annual Conference

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Bioethics and Paediatrics: Future development and challenges

Conference Book



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Acknowledgments

On behalf of the International Society for Clinical Bioethics we cordially welcome to the XV Annual Conference under the theme Bioethics and Pediatrics: Future development and challenges.

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About us

The XV Annual Conference of the International Society for Clinical Bioethics is organized in conjunction with the Borja Institute of Bioethics-Ramon Llull University, the Institut de Recerca Sant Joan de Déu and the Sant Joan de Déu Barcelona Children's Hospital.

The [International Society for Clinical Bioethics](#) (ISCB) was founded in June 2003 with the aim to facilitate contacts and information exchange between those working in clinical bioethics and related fields in different parts of the world, encouraging the development of research and teaching in clinical bioethics and related fields.

The ISCB aims to be truly international, linking all those working in clinical bioethics and related fields, facilitating mutual contact, and encouraging the discussion of clinical aspects in bioethics.

The Society exists for educational and scientific purposes, and not for the purpose of making profits for its members or for any other person or organisation, with the following educational and scientific objectives:

- To facilitate contacts and the exchange of information between those working in clinical bioethics and related fields in different parts of the world;
- To organise and promote international workshops, seminars and conferences in clinical bioethics and related fields;
- To publish bioethical newsletters, volumes and other types of publications;
- To encourage the development of research and teaching in clinical bioethics and related fields;
- To uphold the value of free, open and reasoned discussion on issues in clinical bioethics and related fields.

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

It offers a University Master and several University Expert Certificates in Bioethics, and different assessment services. In addition, the Borja Institute organizes and participates in courses, conferences and round-table discussions with the aim to encourage interdisciplinary dialogue between scientists and humanists as a means to integrating scientific knowledge and ethical sensibility and finding appropriate ways to solve the

problems arising from conflicts between technical views of reality and the cultural and social values.

The [Institut de Recerca Sant Joan de Déu](#) (IRSJD) addresses research from the standpoint of the human development life cycle, directing research activity towards biological and psychological problems related to pediatric diseases and adult health problems which can originate and develop in childhood. This scientific and technological knowledge is the ideal platform to offer innovative clinical, diagnostic, therapeutic and preventive solutions to patients in their project of personal and social life.

The IRSJD aims to become a benchmark internationally in biomedical research in paediatric age, but also with an interest in global human development. Our general hypothesis is that events and interventions that occur at different stages of the individual's life, such as the fetus, newborn, childhood, adolescence, and early adulthood are the basis for adequate and healthy psychological, biological and social development. Early therapeutic interventions against interruptions or health problems in the paediatric age will have a positive impact on health or disease status in adults.

The [SJD Barcelona Children's Hospital](#) (HSJD) is a private, non-profit institution that is dedicated to public service. It is a member of the Brothers Hospitallers of Saint John of God, which manages more than 300 healthcare centres in 50 countries around the world and serves the most vulnerable groups in hospitals, health centres, social services and religious communities.

Since 1867, the HSJD has been dedicated to comprehensive care for women, children and adolescents, and has become one of the most important specialised paediatric centres in Europe. Care is based on the multidisciplinary work of its professionals.

Through the [Sant Joan de Déu Research Foundation](#) (FSJD), the hospital conducts research to find new and better treatments for paediatric diseases. As a university hospital, it contributes to the training of health professionals, together with the University of Barcelona. Their goal is not only to promote and encourage the training of their professionals in order to improve the health of their patients and the community, but also to advance scientific and human knowledge.

Program

Children are not miniature adults. Childhood is a time with its own characteristics and therefore with its own needs, and this fact is also applied in the field of Bioethics. Childhood has been considered as an age of vulnerability and protection, but overprotection can lead to deprotection. Some areas in ethics, such as research (e.g., good clinical practice, risk-based approach, etc.) or as clinics (e.g., oncology, major surgery, transplantation, robotics, nanotechnology, etc.) require a specific paediatric approach.

The participation of children and adolescents in healthcare processes and research decisions is a new challenge. It requires not only a change of attitudes towards minors, but also acquiring knowledge and skills to be able to develop shared decision-making and information processes. Children are not only our future, they are also our present.

That's why the XV Annual Conference of the International Society for Clinical Bioethics will discuss about Bioethics and Paediatrics under the topic Bioethics and Pediatrics: Future development and challenges. The XV Annual Conference will feature keynote lectures from experts, and parallel sessions focusing the attention in the following topics:

Global bioethics

- Bios and ethics

Clinical practice and research in paediatrics

- Good clinical practice, risk-based approach, and ethics in paediatrics
- Clinical trials and paediatrics
- Paediatric oncology
- Paediatric major surgery (e.g., gender reassignment surgery, transplantation)
- New technologies, robotics, and nanotechnology in paediatrics
- Paediatric research in Europe

Anthropological, social, and legal considerations in paediatrics

- Children immigration in 21th century
- Anthropological and social research in children and adolescents
- Data collection and data protection in paediatrics
- Informed consent and decision making process in children and adolescents

Keynote speakers

KIDS Barcelona

The project KIDS Barcelona is part of the global project "Kids and Families Impacting Disease Through Science (KIDS)" within the International Children's Advisory Network (ICAN). The project consists of a group of children and teenagers who act as a Scientific Council in **SJD Barcelona Children's Hospital (HSJD)**. They are involved in the processes of comprehension, communication and improvement of the medical innovation's methods that impact children and teenagers, ensuring, in this way, the voice of the children and their families within the medicine, research and innovation.

The group KIDS Barcelona was created in 2015. Nowadays, it consists of 16 teenagers, aged 12 to 17 years, who have been trained in the four main areas of the project: Biomedicine, Research, Innovation and Clinical trials. The trainers were the professionals and partners of the HSJD, who were able to share their experience and expertise with everyone.

The project KIDS Barcelona seeks to answer to the following needs and goals:

- To teach and defend medicine, research and innovation that improves children's health and treatment, by placing young people in the center of our field of work.
- To promote a consulting process in the hospital, by including teenagers' voice and opinion in all the research projects that impacts them.
- To involve teenagers in the detection of unfulfilled pediatric needs.
- To plan and perform, from the pediatric perspective, all the processes that take action in the development of a clinical trial (e.g. assent document).

KIDS groups are also entitled as Young Persons' Advisory Groups (YPAG) and are acknowledged internationally by the regulators as well as by the pharmaceutical industry, recognized as a youth group trained and empowered by a research centre.

Joana Claverol

Joana Claverol studied Biology at the Universitat Autònoma de Barcelona (UAB) and holds a master's degree in Clinical Trials Monitoring (UAB) and a master's degree in Pharmaceutical Marketing (Pompeu Fabra University). Since 2012, she is Clinical Research Unit Manager at SJD Barcelona Children's Hospital (Sant Joan de Déu Research Foundation) and Director of the Clinical Research Unit at SJD Barcelona Children's Hospital.

Her many years of work in medical departments of pharmaceutical industries have provided her with great experience in affiliate Medical Department, Clinical Development and Medical Affairs; wide experience on clinical study management; deep knowledge of commercialization and business practices; knowledge of pharmaceutical product development, product lifecycle and commercialization process with advanced understanding of Clinical Operations, Commercial, Marketing, Regulatory, and Medical Affairs functions; therapeutic area and products expertise; cross-functional teams and teamwork fostering; and finance and budgeting experience.

Mark A. Turner

Mark Turner is a Neonatologist and obtained a PhD in Medicine with a study on Placental Physiology. He is currently Reader in Neonatology (Clinical) at the University of Liverpool and Honorary Consultant Neonatologist at Liverpool Women's Hospital (United Kingdom). His Research Interests are driven by clinical practice and centre on Early Phase (exploratory) drug development in neonates and young infants; Medicines Safety in neonates and older children; and Research infrastructures. He is author or co-author of more than 150 publications about drug development and safety in children and also about other subjects on Obstetrics, Neonatology and Paediatrics.

He works to develop efficient medicines research infrastructure in Europe and globally as Chair of the European Network for Paediatric Research at the European Medicines Agency (EnprEMA), co-Director of the International Neonatal Consortium and as co-Scientific Coordinator of the IMI2-funded c4c project: Collaborative Network for European Clinical Trials 4 Children.

His approach to research ethics is informed by extensive work as a broker between families, industry, regulators and clinicians.

Hans-Martin Sass

Hans-Martin Sass is a bioethicist, senior Research Scholar Emeritus at the Kennedy Institute of Ethics, Georgetown University, Washington DC, United States of America, professor of Philosophy Emeritus at the Ruhr University, Bochum, Germany, and honorary Professor at the Peking Union Medical College, Beijing, China.

He holds academic positions at People's University of China and Peking Union Medical College (Beijing, China), and at the Bochum Centre for Medical Ethics (Bochum, Germany), which he helped found in 1985. Professor Sass is editor of the *Ethik in der*

Praxis / Practical Ethics series at Lit Verlag (Münster, Germany) and the Medizinethische Materialien (Bochum) and the author of over 250 articles and books. He was a member of the International Bioethics Committee of UNESCO and is a member of many international and national advisory bodies and to philosophical and bioethical journals.

An expert in European continental philosophy, Dr Sass has published widely on Hegel, Marx, 19th- and 20th-century German philosophy, and liberal political theory. During his research, teaching, and consulting in cultural risk assessment, research ethics, clinical ethics, and public-health ethics, he developed cross-cultural perspectives in the major fields of bioethics (based on concepts of personal and professional responsibility), regulated markets, mutual trust, and partnership ethics.

Montserrat Esquerda

Montse Esquerda is a Paediatrician and holds a degree on Psychology. She obtained a PhD in Medicine (Universitat Autònoma de Barcelona) with a study on Focal segmental glomerulosclerosis. She has also a master degree in Bioethics and Law (University of Barcelona). Her Research Interests comprise Ethical criteria for the distribution of resources; moral development, empathy and burnout in medical and health students and health professionals; health decision in children and adolescents; and ethical aspects at the end of life. Dr Esquerda is the author or co-author of numerous publications in these fields.

She is currently General Director of the Borja Institute of Bioethics-Ramon Llull University, and works as a Paediatric Psychiatrist at Sant Joan de Déu child and adolescent mental health center at Lleida (Catalonia, Spain). Dr Esquerda is also Associate professor of Bioethics at the University of Lleida and president of the Deontologic Commission of the Official College of Physicians of Lleida, and she participates as a member of several advisory commissions in the field of Bioethics.

Keynote Lectures

The voice of patients and young children in the decision-making process

Author/s: Claverol, Joana¹; Navarro, Dolors

¹ Clinical Research Unit at SJD Barcelona Children's Hospital. Barcelona, Spain

Abstract:

Patient centered medicine requires their involvement in the different fields that affect their health. When we are talking about children, a trusted way to include the patient's perspective in the different activities and projects of pediatric hospitals is with the establishment of Young Person's Advisory Groups (YPAG) , a trained group of patients and young people linked to research institutions. The goal of YPAG is to increase the input and influence of children and their families/carers into the development of clinical research, ensuring the voice of patients and young children in the decision-making process.

Our Clinical Research Unit has already identified the difficulty that faces our patients when reading the assent document and other issues regarding clinical trials. The YPAG of Hospital Sant Joan de Déu has developed a study to evaluate the information given to participants during the informed consent process in the clinical trials. The outcome of this study is a guideline including the young patient's perspective with recommendations for the ethics committee, for the researchers and for the drug companies about the content and format that better fit the children.

Despite that there isn't a general international consensus about the minimum age in which young patients should sign the informed consent (assent document) from 8 to 12 years old up to 18 is the most common recommendation. Summary with the guidelines about content and format of the assent document:

https://www.rarecommons.org/files/aaff_eupati_english.pdf

The landscape of the pediatric clinical trials will change dramatically in a close future. A new pan-European pediatric clinical trials network, named conect4children, is being established with the funds of the Innovative Medicines Initiative. C4c is going to centralize at European level the trials addressed to minors in a model that includes the voice of the patient as a cross-cutting activity. From the point of view of regulators, the Paediatric Committee of the European Medicines Agency (PDCO) has established a framework for

the involvement of young patients in the activities of the agency. Both initiatives and the aim to offer better medicines for children encouraged our institution with the other YPAGs that exist around Europe to set up eYPAGnet. This is the European YPAG network that has the recognition of EnprEMA and that is working to offer a single point of contact for all the stakeholders ensuring standardized methodologies to involve minors across the lifecycle of drug development.

YPAG collaboration gives a good example that patient's involvement directly impacts the quality of the clinical research projects in pediatrics in identify new research questions, give feedback, influence content and design of proposed research, ensure the quality of educational materials, etc. Also it's suitable process to anticipate and facilitate the decision-making process done by children and young patients.

Paediatrics and Clinical Research: a clinician's view of participant centredness and the Clinical Trials Regulation

Author/s: Turner, Mark A.¹

¹ Liverpool, United Kingdom

Abstract:

Research in babies, children and young people is vital to the improvement of health care and promotion of wellbeing in these populations. All research needs to be carefully justified and appropriate to the participants. Benefits, harms and procedures need to be acceptable to the participants. This presentation will initially survey how these principles interface with the needs for research, with a focus on the development of medicines. The thesis of this presentation is that research should be focused on the participants (and their families). We will assess how stakeholders can promote or impede participant-centredness. This will include a review of the potential impact of the Clinical Trials Regulation on participant-centred design and review of research involving babies, children and young people

Bios and ethics in our complex adaptable systems. Responsibilities towards our Children and our Globe

Author/s: Sass, Hans-Martin¹

¹ Georgetown University, Washington DC. Ruhr University, Bochum, Germany. Beijing, China

Abstract:

We, our bodies and spirits and our natural and social biotopes are complex adaptable systems [CAS's], interdependent and vulnerable within natural, cultural and political biotopes, longing for life, health and happiness. Clinical and pediatric expertise and ethics also are integrated in the many fields of competence and care for our integrated bios and for sustainable biotopes in nature and society. A Bioethical Imperative calls for protecting the complex and interdependent bios in nature and agriculture and in our human social, economic, corporate, cultural, and political bodies for the benefit of our children and ourselves, and for discussing 'health' and 'improvement' in ethical and not only in technical terms. The protection and promotion of healthy people, sustainable societies, and diverse and stable political bodies depend on basic economic accomplishments, healthy food, harmonious communities, preservation and diversity of cultures and environments, on individual dignity and social recognition, i.e. on gross happiness products [GHP's] and not only on gross national products [GNP's] measured in economic terms only.

Bioethics and Clinical Pediatrics: filling the gaps

Author/s: Esquerda, Montserrat¹

¹ Institut Borja de Bioètica. Barcelona, Spain

Abstract:

It is widely acknowledged that involving children in their own healthcare is associated with: 1) better satisfaction with the medical care received (perceived by both parents and minors); 2) major cooperation on the part of children in treatment (establishment of objectives and treatment plan); 3) promotion of the feeling of control (perceiving the illness as less stressful, the dysfunction decreases and facilitating positive adjustment); and 4) respecting child's abilities, promoting them and encouraging their development. However, ensuring the participation of children in health decision-making remains a major challenge in routine clinical practice.

Clinical bioethics lived its first revolution going beyond paternalism to considering the patient an autonomous person, incorporating the concepts of informed consent and competence. In pediatrics, it was very difficult to incorporate those concepts into the usual clinical practice; specially the concepts of minor maturity and competence in the child.

A second bioethical revolution seems to be starting, changing from the informed consent approach to the shared health decision-making model. This is a much more clinical and dynamic concept, linked to relational autonomy. This approach seems to be easier to apply to clinical pediatric practice, but it requires being able to develop the model to "fill in the gaps".

The participation of children and adolescents in healthcare processes and research decisions is a new challenge. Scherer says, "involving children and adolescents in medical decision making requires finding a balance between their desire for self-determination, their need for support and guidance in making complicated decisions often while under stress, and respecting the rights of parents to manage family decisions with a parenting style and customs consistent with their cultural identity".

"Filling the gaps" requires not only a change of attitude towards minors, but also acquiring knowledge and skills to be able to develop an information process and shared decision-making. "Filling the gaps" requires promoting skills such as listening, communicating and teaching.

Special Session: minors and data protection

Minors, Internet And Technology. Growing and Living Together in a Digital World

Author/s: Catalan Data Protection Authority

Abstract:

The APDCAT invites schools to educate children and their environment in the responsible management of personal data. The project, designed in co-operation with Department of Education will be held annually between February and April in 50 schools throughout Catalonia. The purpose of the project is to provide pupils in the second and third year of ESO compulsory secondary education with guidelines and advice about privacy and the protection of personal information in relation to use of the new technologies. The APDCAT has created a specific blog menorsiprivacitat.cat where schools can meet the program, register and make appropriate monitoring.

The main goal behind this initiative is to raise the awareness of young people and their immediate circle about the need for responsible use of personal information when using the new technologies and Internet. To generate debate and involve minors, schools and families in identifying and disseminating common guidelines for growth and co-existence in a world full of technologies, a world which, as we know, offers many opportunities, but which also involves challenges and risks.

Basically, the initiative revolves around three core ideas: First, a positive attitude to the use of Internet and the new technologies: the starting-point is the conviction that the digital experience is constructive. It fosters positive development in young people as regards all aspects that form part of their present and future personality and their attitude towards the use of the new technologies, which, now and forever, will form part of many of their life experiences. Second, a process of thought and reflection: we want to know what young people think and what interests and worries they have regarding the use of new technologies and Internet. We take as our starting point the conviction that, to define healthy digital habits, we need to listen to them and establish and share guidelines and advice as well as, needless to say, guiding them through this entire process of thought and reflection. Third, continuing action: if we are talking about the digital society, then the space in which we need to interact does not end in the classroom; rather, actions must be continuous, and results already achieved must be added to other initiatives with similar

aims. We want to enter the classroom, but we also want to inform adults that form part of the young people's immediate environment about what we did in the classroom, so they can reinforce the guidance and advice that we have provided. This continuity also includes organising a conference, open to all, at which the young people will be, to a large extent, the protagonists.

Parallel Sessions

The Right of Self-determination or the Right of Proxy Consent for Guardians of Legally Incompetent Children?

Author/s:

Awaya, Tsuyoshi¹

¹ Dean, Faculty of Law, Okayama Shoka University. Professor Emeritus, Okayama University. Okayama, Japan

Abstract:

When a child is without legal competence, do the child's guardians (e.g., parents or legally-appointed adults responsible for the child) have the right to self-determination regarding the implementation of medical treatments by medical institutions? Naturally, guardians have no right to determine what medical treatments can be conducted by a medical institution if their child is legally competent. Legally competent children are understood to be capable of self-determination. But what of children who are without legal competence and in need of medical attention? In Japan, there is a misunderstanding that guardians have the right to self-determination in such cases. In my report, I will explain this misunderstanding with one such example. My report ultimately concludes that guardians do not have the right to self-determination regarding the implementation of medical treatments by medical institutions upon their children if the children are without legal competence. Rather, the guardians only have the right to proxy consent so long as the proxy consent is in the interest (or is non-detrimental) to the children in question.

Keywords:

Autonomy, legal competence, self-determination, children

Neuroenhancement and vulnerability of minors

Author/s:

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Abstract:

Children are generally considered vulnerable due to their physical and mental immaturity, lack of knowledge and experience, and overall dependency on adults. Normative documents in the field of medicine (e.g. laws, conventions, professional codices) strongly

promote special measures for protecting children in medical treatments and research. In this paper, we intend to examine the case of neuroenhancement in minors. The use of technology to alter human characteristics and capacities beyond the “normal” is considered “human enhancement”, while neuroenhancement refers to the modification of brain processes with the aim of enhancing healthy people. Human enhancement could be seen as the ultimate praise to personal autonomy and freedom: one can exercise the power of making autonomous decisions, providing that others are not hurt in the process. When it comes to the human enhancement of minors, some would claim that the improvement of certain features might be in the child’s best interest. Immersed in super-hero pop culture and driven by the advancement of science and technology, children begin to have different (greater) expectations from themselves, expectations that may exceed the frame of the human being initially given to them. One might ask whether a hypothetical adolescent who wishes to undergo an enhancement procedure should be considered vulnerable and on what grounds.

The brain is an electrochemical organ where synaptic pharmacology simply serves to influence how electrical signals are transmitted. However, non-pharmacological methods with the potential to affect the functioning of the brain have been developed. The two most common are transcranial magnetic stimulation (TMS) and transcranial direct current stimulation (tDCS). Several authors have called for caution in the use of these methods to treat children and adolescents because of the unknown mechanisms of stimulation, short- and long-term side effects and the lack of dosing guidelines and translational studies from adults to children. These methods, especially tDCS, which is low-cost and easy to use, have been increasingly marketed as safe ways to improve cognition, mood, motor functioning, etc. Synaptic and molecular mechanisms of neuronal excitability and plasticity are difficult to study and protocols for the use of TMS and tDCS are often derived from animal studies. A certain amount of tDCS/TMS work has been done on the adult brain, however children and adolescent brains are not simply small adult brains. Excitation and inhibition of neuronal patterns change as the brain develops, as well as long-term potentiation, long-term depression and plasticity. Therefore, changes that these methods could induce in developing brain tissue and consequently their interference with the normal neurodevelopmental processes could have far-reaching health ramifications.

However, neither children/adolescents, nor their parents or guardians, could have sufficient knowledge to apprehend the scope of influence that these methods might exert on their minds and bodies. Therefore, they present a new cause of vulnerability of the adolescent population – accessibility to technical gadgets that cannot be understood and whose use is questionable.

Keywords:

Neuroenhancement, tDCS, TMS, minors, vulnerability

The Place of Big Data in Addressing Emerged Issues in Vaccinology of the 21st Century

Author/s:

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Abstract:

Vaccinology as great achievement of public health of the 20th century nowadays faces doubts, questions and concerns that could be included in the term of vaccine hesitancy. The vaccinology in the 21st century is marked by the emerged antivaccinal movements followed by a variety of attempts and approaches of professionals to resolve them. The globalization in the health care on the one side and great technological achievements on the other side creates the possibilities where an enormous amount of data are publicly available. The professionals based the benefits of vaccination on scientific data. Vaccine hesitancy and antivaccinal movements declare that they based their policy on scientific data too. The first line of facing vaccine hesitancy of parents are primary pediatricians who can testify their own limiting abilities to do so, as well as limiting abilities of other professionals involved in vaccinology. In the situation of an enormous amount of data, one could be drown out and interpreted in various ways. It is clear that the old-fashioned “defense” of great public achievement of the 20 century - vaccinology is no longer appropriate. On the other hand, the search of the literature shows the entry of “Big Data” in the medicine in general and in the public health and vaccinology too. This paper is an attempt to position the role of Big Data (its benefits, traps and ethical implications) in vaccinology in the 21st century based on exploring the literature and our propositions.

Keywords:

Big data, bioethics, Vaccination

The Digital Future of Paediatrics: Bioethical Assessment of Challenges and Opportunities

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Abstract:

"Bioethics is a proactive experience of the future" Boris G. Yudin

New technologies in medicine have always been key triggers for the development of bioethics and the formation of such fundamental ethical principles as the principle of patient autonomy, confidentiality, and explication of new patterns of doctor-patient relationships. The digitization of health care systems in general and pediatrics in particular outlines trends in the transformation of doctor-patient relationship models and changes in patient autonomy and confidentiality standards. The phenomenon of the "digital divide" is well-known in science. In medicine, it is manifested primarily in the fact that for many years patients (especially the elderly) do not always successfully use the possibilities of new technologies: the Internet, computers, telephones etc. in the management of their health conditions. Training courses to address the illiteracy problems in the informatics are being organized in some places. Such a gap in an inverted form could create problems in the future of Paediatrics. Young patients who are more open to innovations and more skilful in search of relevant medical information about their health conditions will be more actively involved in new technologies, and even doctors can lag behind them in finding information and using new devices. The development of digital technologies in medicine also actualized the trend of reformatting understanding of basic relations of medical professionals with patients and their parents in Pediatrics and, in particular, the re-evaluation of the value of technicism, which was the object of medical criticism, at least in Russia, and now dominates in medical ideology. The development of new technologies in medicine involves the strengthening of the autonomy of patients and processes of technomedicalization. In Paediatrics, this trend is expressed not only in relation to teenagers who can use a large array of information from the Internet, independently use health trackers and applications for smartphones. No less important problem in this context is the possible emergence of a third party – Artificial Intelligence-based technologies as a kind of active agent in medical decision-making. Technologies of computer-assisted care, telemedicine, medical robots in the diagnosis, therapy, and

surgery of childhood diseases will provide doctors with new treatment opportunities, but at the same time will contribute to the depersonalization of the doctor - patient (child) relationship, which can be particularly sensitive in childhood. The digitalization of Paediatrics may also lead to a revision of the principle and the practice of confidentiality as part of the general trend of "the end of private life". For example, due to the participation of adolescents in various forums in which they can share information on all matters related to their health conditions. Abstract was supported by the grant of RFBR, project № 17-23-01017-ОГН.

Keywords:

Paediatrics, digitalization, patient autonomy, confidentiality, physician-patient relationship

Medical and psychological problems of children and teenagers who are professionally involved in sports

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In children and teenagers sports there are numerous problems related to both the physiological immaturity of the organism and the psychological perception of the world by an athlete. These imply: 1) health problems with incorrectly portrayed training process and lack of professional medical support, 2) psychological deformation of a person when the child is unable to resist stress, and how they feel towards their fails and victories, 3) wrong point of view on priorities. Starting from the second half of the last century, sport has significantly increased its ratings. By practicing and competing in sports such as gymnastics, figure skating, swimming, many children become very young and successful athletes since the age of 3. For example, O. Korbut, L. Mukhina, T. Lepinski, Yu. Lipnitskaya achieved the highest results at the age of 14. Such success requires constant training of the athlete, which, without taking into account the development of age, can affect health in a positive or a negative way. Special activities "worked out" for the adult exercise, without adapting them to the methods of children exercise and sports, lead to a premature "pumping" of the young athlete, ahead of the formation of the muscular system, the apparatus of movement, disharmonious overall development. Here we aren't even mentioning the amount of time spent on these activities. Victory in sports arenas, admiration of the audience, parents, the press, is what reveals the superiority of one person over other people - all this puts a heavy burden on the shoulders of the child and causes the formation of an antisocial character. Ethical education in the ideas of

Olympism is presented by Pierre de Coubertin, which is the formation of an understanding of the ideology of "fair play". Fair play is known as the moral task of parents, the coach and the team. In professional sports, a person has to face the need to make a moral choice. The athlete faces dilemmas: to lose for money or to play fairly; to use doping or not; to substitute a teammate or not to do so. A young athlete finds it more difficult to resist temptations than an adult. Children sport is not free from the problem of usage doping, therefore the health consequences are more severe. Many scandals are raised to which the reason is - the usage of contraceptives by skaters for the purpose of long-term preservation of the subtle figure, diuretics, steroids, etc. Children require a specific approach to sport of their age, both from a medical and psychological point of view. While working as an athlete (keeping in mind that professional sport is a job!), the child experiences a double portion of responsibilities - he is obliged to combine studies and full-time trainings for many hours. The tremendous strain of all organs and systems with an unbalanced mechanism of medical support does not contribute to the health of the athlete. All these problems require immediate solutions for the development of ethical, healthy, Olympics-based sports.

Keywords:

Children in professional sports, medical and psychological problems, doping, ethics.

The structure of "QOL". A philosophical proposal for making scales experience

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Abstract:

"Happiness" is one of the greatest concerns for people, but it is difficult to find out its general definition. The sense and how to approach is different depending on each person. Nonetheless, it is necessary for government agencies or academic organizations to measure "happiness." Indeed, various QOL scales have been developed and widely used today in medicine, health care, psychology or economics.

Here we try to maximize the possibility to define "happiness." For example, Aristotle asked for happiness (the highest good) in a human logical activity. Bentham reduced happiness to feelings of pleasure or pain. Meiji Japan's Philosopher Amane Nishi proposed "Health, Wisdom, Wealth" as the second best means of happiness. As far as we compare the above and other examples, we think "happiness" could be defined as "satisfaction-feelings with human activities."

At the core of that definition are "human activities." What are they and how to get them? In the happiness theories or QOL scales proposed so far, indicators have been drawn from individual or cultural experiences. For this reason, those theories or scales stay on the level of empirical enumeration and generalization. This point similarly applies to Aristotle, Bentham, Maslow or M. Nussbaum. There is lack of necessity of indicators and their interrelation, that is, rationality but different from AI's.

In this presentation, first of all, "human life" is divided into three levels: biological life (survival), daily life (communicational activity), and whole life (lifetime). And "quality" is also divided into objective conditions and subjective states. Next, analyzing the interpretation-process of face-to-face communication, we take out "four-division relation" as its logic, and make it intuitive as "four-function diagram." Based on that framework, we grasp human life as the functional pattern, that is, "structure". From the viewpoint of structure, three life-levels are isomorphic, and objective and subjective indicators are correlated on the same platform. Not only empirical generalization and statistical calculation, but also philosophical abduction is necessary for the QOL scale. Finally we make a new proposal of QOL scale.

Keywords:

Quality of Life, Philosophy of Medicine, Ethics.

Pediatric well-being by virtual Barça experience

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Abstract:

As highlighted by the European Commission, there is a direct relationship between the welfare of children and the reduction of inequalities (poverty, other capacities, illness, discrimination and other causes of social exclusion), through the promotion of emotional, social, cognitive and physical development. According to the 2012 Study on the positive effect of fulfilling a desire in sick children, from the Complutense University of Madrid, with the support of the Official Association of Psychologists of Madrid, there is evidence that shows us that the emotional intensity with which children live in a situation that excites them, is related to improved results in the quality of life of children, with less anxiety in relation to treatments, in improving their social relationships and in better cognitive

functioning . This is confirmed by the studies of Seligman, 2011 and Fredrickson (2002), which demonstrate the importance of increasing the number and frequency of experiences that generate positive emotions during the difficult times of life in order to generate resilience, which serves to break negative cycles of exclusion situations. Specifically, the project includes the focus of the ChildLife model, in the hospital setting, which defends healthcare centred on the needs of children and encourages emotional stability. In this regard, it is necessary to adapt the hospital settings and have the resources that contribute to their well-being. Robotics helps to improve the quality of life of children: Increasingly, telepresence robots are being incorporated into hospital equipment and to the domiciles (where the patients remain long isolated periods). As Awabot proves, robotics allow patients to connect with their environment and loved ones, and healthcare professionals incorporate innovative strategies for the examination and follow-up of patients; aspects which contribute to the welfare of patients in hospital. Especially with children, telepresence robots allow young patients to break their isolation through a virtual connection, visit a museum, go to a concert or event, etc. Various experiences show that robotics is a tool with a clear potential to improve quality of life. The work carried out by Jordi Albó and Alexandre Barco (Ramon Llull University), Miquel Domènech (Universitat Autònoma de Barcelona), Cecilio Angulo (Polytechnic University of Catalonia), among many others, indicate that these types of devices help to reduce pain and anxiety in hospitalised children during clinical trials. A study from the University of Calgary showed that, from the total number of children who suffer more stress and anxiety when treated, 50% take better medical tests if they interact with a robot during the treatment. The situations of admission in a hospital and undergoing treatment are moments of pain, uncertainty and incomprehension for patients and their families, but especially for children. In that moments, is important: to increase the number and frequency of experiences that helps to forget the illness, to generate positive emotions to children and guarantee that hospitals, where children spend such a large amount of time, and to offer exciting and stimulating experiences. According with this approach, Barça Foundation implements a project called "Robot Pol" aimed to improve hospitalised children life quality, collaborating with leading paediatrics centres in Catalonia, where many of the patients are suffering from serious illness. This project is based on the use of a robot with a remote controlled system; so children who are bedridden (at hospital or at home), can operate it from a computer with camera, and enjoy Barça tour experience..

Keywords:

Robotics, paediatrics, qualit of life

The “Procedural justice” as a principle of medical ethics

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Abstract:

Clinical ethics matters how people should act in the clinical setting. Thus the major concerns include the analysis of dilemmas originating from conflict of ethical principles. For example, the famous framework formulated by Beauchamp and Childress in 1979 contains four principles, namely autonomy, beneficence, non-maleficence and justice, which specify the origins of dilemmas and give the sources of ethical discussions. In this presentation, “procedural justice” as an independent ethical principle that potentially provides a novel key to solve conventional ethical dilemmas is discussed. Indeed, justice is one of the “Four Principles” of Beauchamp and Childress. However this term in the conventional context usually concerns fairness and equality in the distribution of social and economical resources, in which the “substantive justice” is in focus. In contrast, procedural justice concerns the process per se that should protect human rights of each person concerned. Paradoxically, but as a logical consequence, procedural justice gives a pardon for restrictions on rights. The examples include criminal and civil due process of law, which is a legal concept synonymous with procedural justice. Procedural justice may potentially solve ethical situations in which restrictions on the freedom of particular persons are inevitable or those in which an achievement of valid agreement of persons concerned is impossible. For example, the principle may provide a key to harmonize the freedom of people who need care, such as demented elderly people, and the burden of family care-givers who are socially forced to be in charge of care.

Keywords:

Competence, arbitration, advocacy, proxy agreement

The case of Charlie Gard in the mirror of bioethics

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Abstract:

In the UK, the Great Ormond Street Hospital recently completed the legal struggle for the life of a child, who soon after birth found a rare genetic disease. Ten month old Charlie Gard was in hospital in the intensive care unit, but was disconnected from the life support system, although his parents were against, but they lost a lawsuit for the right to take his son to the United States for experimental treatment. This case again raised a number of bioethical issues that concern not only the issues of passive and active euthanasia in Pediatrics, but also the rights of the child and his parents, who were not allowed to decide whether their son will live or not, were not allowed even to decide when and where he will die. Based on numerous and highly qualified examinations, the British courts concluded that, apparently, Charlie was experiencing constant pain and agony. The passage of experimental treatment without the prospect of success would not bring him any benefits and only prolong his suffering, as it was stated in the decision of the Strasbourg court. The court also lifted the ban on disconnecting the child from the life support apparatus.

This case demonstrated a phenomenon that is widespread in the world, associated with the strengthening of liberalism in modern medical practice. All this is reflected in three main trends. First, we are talking about the fact that, according to how the British courts and the ECHR, to prolong the life of little Charlie means to cause him "substantial harm." It is better for the infant to die in order to stop suffering related to his illness, i.e. not "to kill" but "to grant a merciful death". Secondly, the "spread of the culture of death", when death is declared a "right", the cases of realization of this "right" is becoming more and less restrictions. There's the obvious reason – to kill human beings is much easier than to deal with him. Third, the totalitarian nature of the "culture of death", where bureaucratic structures – both British and international – believe that they have infinitely more rights to the child than his parents – and that it is up to them to decide whether to die now or to make another attempt at salvation.

This is a very indicative manifestation of the "culture of death" and it marks a very profound shift in the mentality of the political and media elite of Western Europe. From our point of view it is in contradiction with the basic bioethical principles based on anthropocentrism and humanistic theory. It is also fundamentally hostile to the family, childhood, life in general.

Keywords:

Bioethics, pediatrics, euthanasia

Is the privacy of information protected in the Neonatal Intensive Care Unit? An observational study

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Abstract:

Introduction: The Clinical Bioethics Committee (CBC) in our institution has recently set a quality project to improve the clinical practices and knowledge about confidentiality, addressed to all the professionals caring from patients. The Working Group on Confidentiality has published a written guideline and is performing teaching activities using role-play simulations. A growing number of physicians, nurses and auxiliary staff are attending these sessions. Two members of the CBC working in the Neonatal Intensive Care Unit (NICU), concerned about the difficulties in preserving intimacy and privacy of information in this area, decided to conduct an observational study. The objectives were to check the quality of the confidentiality in the NICU area, and to find out opportunities for education and improvement. The NICU is designed according to traditional standards: one single room including 12 incubators and a variable number of cots. Parents are allowed to enter 24 hours a day, and grandparents and siblings can also visit the unit for short periods of time. No identification is needed for anybody entering the NICU. The doors are automatically opened without security codes. Prior to discharge, some babies are cared in family rooms next to the NICU, from where they are carried to the main area to check weight or vital signs, once or twice a day.

Methods: This is an observational study performed during one month period (June 2018) during the morning shift, from Mondays to Fridays. A nurse and a neonatologist collected any situations of violation of confidentiality, that were predefined. The professional category of the staff who acted was also collected. The observed team was not aware of the observations.

Results: During a total observation time of 147 hours, 25 situations of violation of the confidentiality were encountered. 48% (12/25) were comments spoken in loud voice about patients in the NICU area or in annexed areas, 24% (6/25) were related to leave medical documentation or computer screens available to anybody or to inform parents in a way that could be listened to parents of other babies, 12% (3/25) were phone conversations about patients in loud voice, 4% (1/25) were to answer questions to parents or relatives or other babies, and 12% (3/25) other situations. Doctors and nurses were involved in a similar number of cases. **Comments:** The medical and personal information of the patients in the NICU is often exposed and shared with parents of other patients and non-related professionals. The architectural design of the traditional NICUs, some socio-cultural uses in countries from Southern Europe and the difficulties in changing attitudes

are the critical points to focus in to start a quality educational project to protect the right to intimacy and confidentiality of the small and vulnerable patients admitted to the NICUs.

Keywords:

Confidentiality, NICU

Surrogate motherhood

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Abstract:

All the currently known effects of surrogate motherhood (SM) on the health of embryos, children, women and men, as well as its potential impact on the stability of the marriage, family, family ties, community and society, now and in the future, were analyzed. The intention of this discussion is to shine the light of truth on the fundamental facts, research and findings in various scientific fields, take everything into account, and then summarize and weigh the positive and negative conclusions regarding SM and medically assisted reproduction (MAR), in order to arrive at a fair scientific assessment and form sound ethical positions on their applications in human reproduction. The ratio between the very few benefits and the many times greater harms incurred by the participants in SM and MAR, the community in which they live and the society as a whole is considered. By consenting to commercial SM for a given time, a woman is not only selling her reproductive organs but also her entire body and being. SM also involves services established for the care, upbringing, education and protection of the child. By presenting and confronting the various factors pertaining to the challenges of unnatural human reproduction, this discussion has led to a comprehensive understanding, conclusions and positions that provide useful information on SM, as the most complicated form of human reproduction. Interdisciplinary research methods were applied. The convergence of numerous factors toward the same focal point of observation was considered logically. Analysis has shown that achieving pregnancy through the complicated methodology of MAR and SM brings great disorder into interpersonal relationships and exhausts them by artificially multiplying problems, humiliating the participants, and rupturing the relationship between the surrogate mother and the child she has borne, as well as creating an adverse overall environment for the child's normal growth and development. The important ethical issues raised include the relationship between a noble goal (helping oneself and one's

family) and the use of negative means to achieve it (the breakdown of marriage, human and maternal dignity; abandonment of one's family, especially one's existing children). It is doubtful that complex MAR and SM are really in the best interests of the child, since he or she may experience psychological repercussions owing to problems arising from establishing his or her own identity, as well as confusion concerning family ties. Should medicine do everything that it can?

Keywords:

Surrogate motherhood, medically assisted reproduction, parenthood, cost benefit

Child's Decision Making in Medical Care and Medical Neglect

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Abstract:

In general, if a patient lacks the capacity to express intent, someone has to sign a medical contract on his or her behalf. However, this medical contract should not be seen as an agreement covering all medical practices. In other words, providing consent to each medical practice is something different from the capability to conclude a medical contract. Thus, a theory states that a patient has the capability to agree on individual medical practices even if he or she is a minor. So, what happens if the patient lacks even this capability? In such a case, taking the opinion of parents is the popular solution adopted in many countries, although the legal procedures vary from country to country. However, parents do not always wish that their children undergo treatment. The parents' intentions may reflect an ethically acceptable decision based on deliberation or may be a case of conflict of interest between them and their children. In pediatric medicine, figuring out who will decide on the treatment or its discontinuation is a big problem. Some researchers identify the following two scenarios as being important for this problem: 1) The idea of the parents is different from the dominant idea in society, and 2) The child's decision is different from that of the parents (this is the case when a child can express his or her intention).

Under these circumstances, children may miss out on the opportunity to receive effective treatment. This is the so-called problem of "medical neglect." Ethical, legal, and sociological studies on this problem are being conducted in each country. Some countries have responded to the problem by bringing in legislations to regulate it or by formulating

a set of guidelines. The country to which the presenter belongs is no exception; it has witnessed not only conflicts among the various theories but also political dramas. Of course, there are examples of judgments, such as those by the Domestic Relations Court. In one case, the parents did not respond positively to doctors despite the latter explaining many times the treatment of a minor suffering from ocular tumors. Therefore, the director of the child guidance center requested temporary termination of parental rights. Unfortunately, it is difficult to share all the details of the case in the limited time I have. Thus, this presentation seeks to report on the current status of the discussion by focusing on specific cases; however, these case reports contain some unclear parts. Because the problem is within a family, there are cases where the name of the party, the disease, and the treatment method are not disclosed for the sake of privacy protection. Further, it is not easy for researchers to obtain such information. Although these cases contain limited information, they can shed light on problems common to each country.

Keywords:

Decision making, parental authority, Domestic Affairs Trial Law, medical neglect

Responsibility towards health literacy improvement of our children: Health literacy improvement of the 8th grade students of the Elementary School "R.K. Jeretov Opatija" on communication, emotions and reproductive health

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Abstract:

Background: The culture of proactive thinking about one's own reproductive health is insufficiently developed among school-aged children, which leads to abortions, sexually transmitted diseases, and neoplasms in the population up to 19 years. The need for their empowerment through proactive approaches by the system is emphasized. Current promotion of health education varies considerably between Croatian counties and, given the presented public-health indicators, is either insufficient or requires a change in methodology. Possible direction for future action may be the strengthening of extracurricular/curricular activities to improve reproductive health literacy (HL) among school-aged children. Aim: To assess and improve HL on reproductive health of 8th grade

students of the Elementary School "R. K. Jeretov Opatija". Examinees and methods: During 2015/2016 and 2016/2017 academic year, a cycle of workshops was held for the 8th grade students. Prior to the workshops, approvals of the directors of the School and the Institute and parents were obtained. In 2016 there were 51 students (31 girls and 20 boys) participating in the workshops, while in 2017 there were 69 (33 girls and 36 boys) of them. Work in a small group was selected as a method. Students were divided into sub-groups of girls and boys. Workshops were held in the school library through three thematic meetings using general-to-specific approach: communication – emotions – reproductive health. An anonymous survey was completed before the start and at the end of the workshops-cycle. Results: Gender differences were noted. Girls think they know more about emotions ($z=2.15$, $p<0.05$), and boys think they know more about sex ($z=2.60$, $p<0.01$). Boys feel more comfortable about their body ($z=2.17$, $p<0.05$). Mutual respect in a relationship is more important to girls ($z=2.40$, $p<0.05$). In both genders there are sexually active individuals. The workshops were graded as useful (96%). Average rating (M) was 4.93. School Council adopted the workshops as integral part of School curriculum from the 2017/2018 academic year on. Conclusion: These data provide the basis for HL interventions, by the means of synchronous approach by the health and education professionals. The HL improvement activities should be placed in developmental and contextually adequate environments that will actively involve adolescents in the learning process. Sexuality in the 21st century should not be a taboo. Health literacy changes health behaviour.

Keywords:

Health literacy, reproductive health, school-aged children, responsibility, Croatia

Birth Delay, Decreased Fertility, Infertility, demographic breakdown of Croatia and Europe

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Abstract:

Demographic image of Croatia, Europe and most western countries is characterized by longstanding decrease of natality. Moreover, in the last few years immigration into economically stable countries of the Union has been contributing to the already dire situation. The demographic image is characterized by serious depopulation of the country, with many of consequences for the economy, productivity, sustainability of pension system, healthcare system and general functioning of the social system as we

know it. Elaboration: A traditional three-generation rural family has lost its appearance over the past fifty years due to deagrarianization, industrialization and emigration. Such an untraditional way of the above-mentioned family life has greatly affected fertility and reduced fertility in the society. Similar trends can be found in the Republic of Croatia, as well as in other western countries in North America and Europe. Mills from the Netherlands (Mills at all, 2011, p. 848-860) combines causes of the family transformation. She elaborates that efficient contraception that appeared on the market in 1960s has enabled women to postpone birth for more convenient time in their lives. Women are being offered the option of education and employment, careers, additional earnings, resulting in the mass delay of birthing. Discussion: Accepting each theory as a part of one greater and more complex picture, only one constant occurs. This constant is widely accepted delay of birthing for later reproductive years. It is now thought that the optimal time for the first birth of child is about 35 years of age. Knowing that the optimal fertility time with the highest fertility rate is between 20 – 27 years of age, after which it declines annually by 10%, we have accepted reduced fertility and infertility as an alternative to postponing birth. Fertility rate at the age of 32- 35 years is around 22% of maximum fertility. The risk of spontaneous abortion and premature birth has risen. Also, the health of women and children during pregnancy in inappropriate years has significantly increased the risk of possible complications. We must mention here health problems such as obesity, hypertension, gestational diabetes, hypothyroidism. Children born in those conditions have a higher risk of mental and physical handicaps of various profiles. Genetic prenatal diagnostics today is widely spread and mostly based on finding chromosomal aberrations such as trisomy 21, 18, 13. However, in literature we can rarely find terms such as deletion, microdeletion and defragmentation of the sperm chromosome or egg cells (oocyte) that are associated with older age. Conclusion: We should reinforce the concept of the family way of life which we have neglected over the past decades. The goal of upbringing should guide young people to comprehend the importance of family and its right-timed conceiving. In order to change the negative stance towards family and children, it is necessary to act at multiple levels such as upbringing, education, examples in family, school and religious community.

Keywords:

Birth Delay, Decreased Fertility, Infertility, demographic breakdown

Bioethics of Children's autonomy in medical decision-making

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Abstract:

Autonomy is one of the most important principles of medical ethics. Do we grant this right to children under the legally recognized adult age? If no, this right is not universally valid. People will argue that usually we use the best interest standard for decision-making in children because they are presumed as lacking the capacity to discern. But as children get older and acquire cognitive skill, experience and emotional maturity, their individual views deserve our attention even though they are still regarded as children for being under the legal adulthood. The new law in Victoria, Australia will require physicians to honor advanced directives written by children from March, 2018. In medical treatment, children should be informed and assented in the language they comprehend in regards to the procedures effecting their wellbeings and health. Nevertheless, in medical practice it is not clear-cut whether a child of a certain age is sufficiently competent for medical decision-making. In human research experiment involving children, parents are approached for consent but more and more countries will require children to express their assent and co-sign the ICF before the experiment is approved to go ahead. A certain level of competence is required for medical decision-making. But when does a person reach that stage? This presentation will discuss that children be allowed to take part in that process as they become more increasingly capable of making choice. Four capacities have been listed as required for medical decision-making, namely, communicating a choice, understanding, reasoning and appreciation. This presentation will also suggest a method to consider if a minor scores high enough to be autonomous in decision-making.

Keywords:

Autonomy, decision-making

Moral-bio-ethical aspects of child trafficking

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Abstract:

The major concern of international immigration in recent time is a human trafficking, which is thought to be the third largest and one of the fastest growing trans-national criminal organizations. The Global Reports on Trafficking in Persons are considering that approximately 4.5 million people are being trafficked around the world, and 27% of all victims, are particularly vulnerable group of children. A lot of them are kidnapped for the different purposes (illegal adoptions, forced labor, child prostitution, child pornography, agreed marriages, organ trafficking,...), but mainly for sex exploitation.

Sex traffickers are using different models of abduction or controlling their victims by manipulative lies, false promises, acts of coercion, threats, intimidations, violence, debt bondages..., and other forms of abuse and compulsion which expose trafficked children to the hard physical and mental violence and extreme medical and somatic concerns, for a life time. This bioethical problem requires an interdisciplinary strategy to facilitate international cooperation in investigating and prosecuting such trafficking, for setting up of an effective mechanism of monitoring, capable of controlling and preventing this crime of violation of human rights. That's why this presentation is going to point out some moral-bio-ethical concerns of the human trafficking raising consciousness to this global issue and to:

- Be familiar with the statistical, sociological and moral-bio-ethical magnitude of the problem of human trafficking!
- To be informed of the identification of vulnerable groups and organized models of Coercion, Recruitment, and Enslavement!
- Be aware of international strategies to combat trafficking!
- To be able to act and mobilize the community for the development and application of preventative models of exploitation!

The bioethical assignment is to awake a social awareness of the proliferation of trafficking problems; a professional involvement for global reaction of exploitation issues and to put

a human dimension of sensibility for especially young vulnerable groups of children trafficking.

Keywords:

Children trafficking, child prostitution, child pornography, child labor, forced marriage, organ trafficking, torture, human rights abuse.

The treatment agreement as a way to encourage child participation in child and adolescent psychiatry

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Abstract:

Background: Children's participation in all matters affecting themselves is guaranteed by human rights documents such as the UN Convention on the Rights of the Child. Yet, patients in child and adolescent psychiatric hospitals suffer from double marginalisation as minors and mentally ill patients, thus, special care should be taken to safeguard their rights. So far, little research efforts have been invested into exploring the means and effects of children's participation in psychiatric decision making. One form of advance care planning are treatment agreements which are already established in some adult psychiatric clinics. Child and adolescent psychiatry could follow this example. **Objective:** We investigated available options for child participation and developed an advance care document for child and adolescent psychiatric hospitals in collaboration with the Child and Adolescent Psychiatric Hospitals at the University of Göttingen. To this aim, we carried out explorative qualitative interviews with hospitalised children, their parents and staff members to explore the need for advance care planning, and we organised two workshops. **Results:** Children, parents and staff members stated several positive effects of a treatment agreement in psychiatry. It could increase child trust, reduce fear and help safeguard respect for the dignity of the child. Both parents and children would expect to profit from increased reliability of the hospital team. Doctors expect positive effects on transparency as well as crisis prevention. Based on this assessment, a treatment agreement document was developed together with staff members, including psychiatrists, a psychotherapist and a nurse, as well as ethicists and a law student. The document comprises an information and an agreement part. **Conclusion:** Supported by hospitalised child and adolescent psychiatric patients, their parents and staff members, we succeeded

in developing a practicable treatment agreement. Once established, this form of advance care planning could contribute to safeguarding minors' participation rights in healthcare decision making.

Keywords:

Advance Care Planning, Treatment Agreement, Child and Adolescent Psychiatry, Participation, Crisis Prevention

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