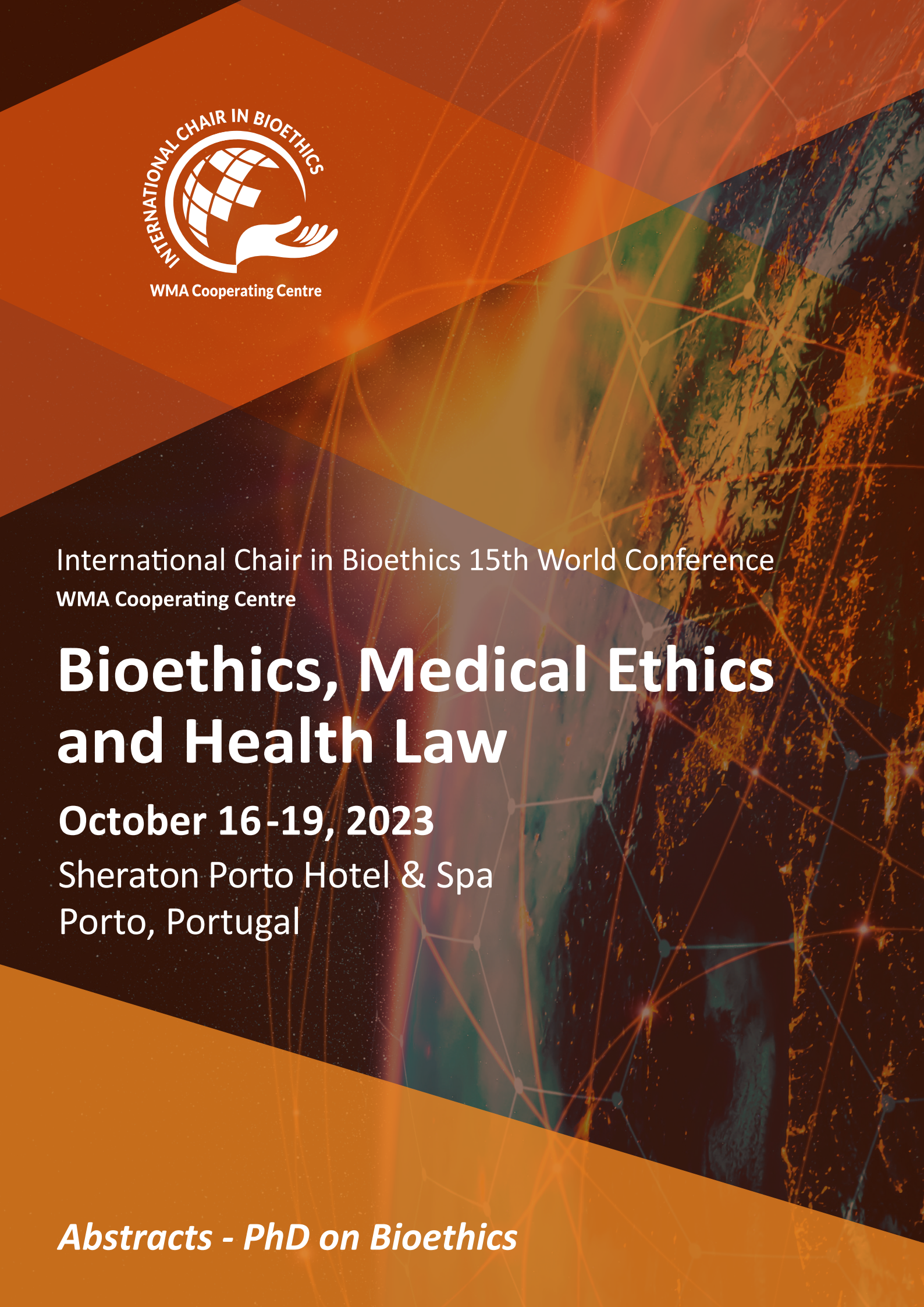

International Chair in Bioethics 15th World Conference

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Bioethics, Medical Ethics and Health Law

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Sheraton Porto Hotel & Spa

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Abstracts - PhD on Bioethics

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ABSTRACTS

PH.D. IN BIOETHICS DEPARTMENT

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Abstracts
Ph.D. in Bioethics Department

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1 Ethical Questions of the Prenatal Diagnosis of Genetic Disease

Rui Nunes

Background: Bioethical questions raised about the prenatal diagnosis of genetic diseases arise because of different individual perceptions of our humanness. The difficulty occurs because the moral status of the human embryo is yet to be defined. The attribution of status to the human embryo presupposes that a profound reflection has been made about the meaning of human life on both its biological and anthropological dimensions. Modern societies adopt a pluralism of ethical beliefs and moral viewpoints that is general secular ethics. The underlying values of this moral pluralism are subject to a permanent tension by the scientific-technological imperative that decisively penetrates the heart of traditional cultures. Bioethics springs naturally from these concerns. It might be argued that human dignity springs from the human being itself as a member of the Homo sapiens species. This naturalistic perspective seems to be an essential element to achieve an anthropological conception of the human person. Also, it is a means to give persons respectability. Human dignity would be the starting point from which an ethical theory could be framed as a foundation of human action. We attempted to fit this perspective on a deontological view of moral life. Pragmatically we adopted the Beauchamp and Childress principlism as an analytical method. This framework is helpful as a guide to human action in the healthcare context. However, we believe that although these principles and rules have strong normative content, they lack a coherent internal structure that solves ethical dilemmas. Eventually, pure deductive reasoning is not always possible, but, instead, a reflective equilibrium between deduction and induction should be accomplished. The final objective is a logical ethical reasoning accepted by common morality.

Objectives: The primary objective of this study was to analyze the ethical questions associated with the prenatal diagnosis of genetic diseases having as background clinical geneticists' opinions about it. Specifically, what the ontological statute of the human embryo is, and the ethical legitimacy of abortion. Also, it might be asked what diseases – following the Human Genome Program – are eligible for prenatal genetic diagnosis (PGD) and preimplantation genetic diagnosis (PIGD). As a secondary objective, it is intended to determine if Recommendation No. R(90)13 of the Committee of Ministers to member states on prenatal genetic screening, prenatal genetic diagnosis, and associated genetic counseling adopted on 21 June 1990 (Council of Europe) is accepted and applied by the Portuguese scientific community.

Method: This is a cross-sectional and quantitative study, with an original questionnaire to understand Portuguese geneticists' opinions about PGD and PIGD. The original quantitative questionnaire was built and validated by an expert committee based on adequate literature. A pre-test with a convenience sample of geneticists was pursued to warrant, the readability, comprehensiveness, clarity, and facial validity of the questionnaire. The total universe of Portuguese genetic centers enrolled. The study sample (excluding the pre-test participants) was collected to ensure representation of the targeted population of geneticists, in terms of gender, years of practice, specialty, and workplace geographic distribution. Participants have provided their free and informed consent, in the questionnaire itself. The study started after the positive opinion from the competent Ethics Committee. The quantitative survey is divided into 2 groups: 1. Demographic data, and 2. Prenatal genetic diagnosis, preimplantation genetic diagnosis, and genetic counselling. In each group of questions, a definition and additional information of key concepts are added so that the participant is fully informed before answering. For data gathering and analysis it was used the Microsoft SPSS. Responses to the survey were statistically described using relative and absolute frequencies, mean and standard deviation or median and interquartile interval, as appropriate.

Results/Conclusions:

1. We defend the thesis that every human being is a member of the moral community from the moment of fertilization due to a wide ontological solidarity. Although the human embryo is not a person, in the philosophical sense because he/she lacks superior mental features – such as consciousness and self-consciousness, preferences, thoughts, conscious desires, feelings, sense of time, rational thought, unification of desires over time, and rational deliberation, the capacity to experience pleasure and pain, to remember one's past actions and mental states, to envisage a future for oneself, to interact and communicate socially, to have long-term interests and to take moral considerations into account in moral choices – he/she should be protected because his internal dynamism is sufficient for him/her to become a person. As a potential person, he/she should be respected. The legal framework should consider the human embryo an actual subject with rights attached to him/her. It follows that human embryo research should be conducted in accordance with the Declaration of Helsinki, promulgated by the World

Medical Association. Nevertheless, some investigation should be carried out if it is beneficial to the embryo and the predictable risks are minimal (stem cell research for instance). It seems to us that a distinction between embryo and pre-embryo pretends to be euphemistic since it is the same human being in different stages of its development. Although we could find some disagreement between geneticists, a reasonable consensus was achieved with regards to the irrelevance of this distinction. However, most geneticists believe that the distinction between viable and inviable embryos is a relevant one, although what grants a particular status to a human entity is the fact of being part of the moral community; not the presence of biological characteristics likely to prevent their development. In short, the recognition of the intrinsic value of each person, due to his rational nature and unrepeatable individuality, crystallizes the notion of human dignity and recognizes the specific singularity of the human being. However, this Kantian conception of human dignity has various consequences. Firstly, the human individual – as a unique and unrepeatable subject, as an individual being – cannot be "instrumentalized" or, in other words, treated as a means and not as the end.

2. Advances in medical genetics have resulted in a comparable increase in interest in genetic counselling. However, opinions differ widely on how directive genetic counselling should be. If any conclusion can be obtained from this inquiry it is that sometimes the counsellors should embrace a more directive approach. Namely, we refer to selected cases of sexual selection. The norms of medical confidentiality require doctors not to divulge information imparted to them by their patients. However, as "the patient" in clinical genetics is frequently the whole family of the index case, information can be helpful to other family members as well. An ethical dilemma might occur when the geneticist wants to disclose genetic data. It might be argued that a right exists that legitimizes this disclosure. The rule of medical confidentiality might be seen as a *prima facie* obligation, to be overridden only by an even stronger moral claim. Some authorities believe that the doctor has a duty to other family members as well. We believe that this perspective is hard to accept, or at least to justify, because it not only undermines autonomy but is contrary to human dignity. Any action that coercively interferes with the right to privacy must have a proportionate moral argument. Prenatal as well as adult screening will increasingly be capable of detecting late onset genetic diseases (Huntington's disease in particular). Although every responsible citizen has not only rights but also social duties (one of these duties is the one associated to the knowledge of one's own genetic endowment) we do not conclude that this social responsibility is illimited. A consensus existed that selective abortion for late onset diseases is difficult to justify morally (diseases that develop at the adult life in the context of predictive medicine).

3. During this study we pointed out the main procedures that might be used during pregnancy to accomplish prenatal diagnosis. It was also stated that preimplantation genetic diagnosis is progressively available. The time has come to put forward a set of ethical questions regarding this technology. It can be an option for couples in genetic risk because it does not involve abortion. However, if the result is positive the embryo will probably be destroyed. Clinical geneticists were aware of this and related ethical problems. It was concluded that preimplantation genetic diagnosis should be used only as a therapeutic weapon and never with the purpose of sexual selection or improvement of physical or affective traits. Even if enhancement genetic engineering would be ethically acceptable there is no consensus about fundamental values which may be presumed to be welcomed by everyone. Until such a consensus is achieved preimplantation diagnosis should not be associated with any kind of enhancement genetic engineering.

4. In developed societies prenatal genetic diagnosis is usually offered when couples are in a well-defined genetic risk group. Nevertheless, not all pregnant women take this option due to particular moral and religious views. Normal human being is a non-existent concept. All of us are in some peculiar way "abnormal" since we are carriers of more than one recessive gene for a genetic disease. It is hard to define the precise limits of individual variation. The concept of normality at the biological level is closely associated with the widely spread expression of quality of life. We believe that quality of life judgements should not be decisive in abortion choices. Geneticists do not believe that only "perfect babies" have the right to exist. On the other hand, extreme situations in which life-sustaining treatment is not suggested by the medical team – as anencephalic foetuses – can be ethically defensible. Probably a proportional reason exists for such an action. Quality of life for the patient should not be confused with the quality or the value of life for others. Nevertheless, couples have a wide range of decision-making capacity with regards to reproductive choices. Geneticists should respect a pregnant woman's opinion if she decides not to procreate. If abortion is at stake, the virtuous physician should always respect the couple's reproductive autonomy notwithstanding his proclaimed right to conscientious objection. Another ethical imperative in healthcare practice is the informed expressed consent of procedures with some risk of physical or mental harm. Prenatal diagnosis is no exception to this rule.

5. Consistent with the results it was concluded that bioethics can be established as a new scientific field even though it has a pluri and transdisciplinary approach. The initial discussion over the concept of bioethics has somehow vanished in the sense of reaching globality. Global bioethics, in this context, means not only universal ethics but also the ethics of life sciences and healthcare. The understanding of this new science played a major role in the development of modern societies. However, bioethics is not only a cultural need but mainly a major challenge. A challenge to human intelligence and liberty as fundamental traits of his personality.

Keywords: Abortion, genetic counselling, preimplantation genetic diagnosis, prenatal genetic diagnosis.

2 Preimplantation Genetic Diagnosis: The Practice, The Technique, The Ethics

Natália Oliva Teles

Following the advances in the techniques of Medically Assisted Reproduction (MAR), 1990 saw the first child born after the development of preimplantation genetic diagnosis. In this analysis, embryos are tested for the presence of genetic anomalies at three to five days after fertilization and only unaffected embryos are transferred to the maternal uterus. The technique offers good prospects to couples at risk for conventional prenatal diagnosis. It is particularly useful where MAR techniques are necessary, in which early embryo selection avoids later termination of pregnancy.

Ethical problems related to this technique start well before the analysis with the need for detailed non-directive genetic counselling, obtaining fully informed consent for the procedure and maintaining strict confidentiality; the main ethical problems are concerned with the status, investigation and manipulating of the embryo, eugenic or sex selection and the provision of resources.

In Portugal, the application of laws concerning regulation of Medically Assisted Reproduction in 2008 has clarified and formalized the medical and laboratory procedures and in some cases fundamentally changed them, particularly in the requirement to cryopreserve all high quality non-transferred embryos and in specifying conditions in which embryo experimentation may be permitted. Overall, as is shown by comparison of questionnaires from 2001 and 2010, the major ethical problems that confront professionals in this area of medicine are related to the beginning of life.

Based on the motives discussed in the thesis and foreseeing some of the difficulties in taking positions for the resolution of such problematic conflicts of ethical attitudes, the great challenge in ethics in the next few generations will be to define the limits of – embryo correction that are considered reasonable and acceptable for the society of the future while never forgetting to apply the four fundamental ethical principles, autonomy, beneficence, non-maleficence and justice.

Keywords: Embryo selection, genetic counselling, preimplantation diagnosis

3 Bioethical Principles Applied in Assisted Abortion During Adolescence

José Humberto Belmino Chaves

Introduction: Provoked abortion is a rather grave problem in the public sector health system and is well recognized by the World Health Organization. It is considered to be provoked when it is the result of any external abortive process, chemical or mechanical. Post abortion curettage represents the second most carried out obstetric procedure at the interning units of the public sector health system, surpassed only by normal birth.

Considering this very fact in March 2005, the Ministry for Health in Brazil has launched the Manual for Technical Standards & Norms to attend to abortion in a humane manner in the public sector hospitals of the *Sistema Único de Saúde* (the Stately run health programme), however it does not recommend the study of the resulting anatomical pathological material. Due to this problematic situation, we have been motivated to examine and evaluate the assistance to adolescents facing the situation of abortion.

Objectives: Considering abortion is a public sector health problem in Brazil, this study work is searching to describe the social demographic, behavioural, clinic, ultra-son graphic, complications, anatomical pathological characteristics and the type of abortion with regards to the motivation in pregnant adolescents, attended to at a hospital from the *Sistema Único de Saúde* in the City of Maceió, State of Alagoas, Brazil, whom were submitted to uterine curettage, in order to bio ethically discuss this fact.

Materials and Methods: It is a transversal descriptive study constituted by 201 pregnant adolescents to whom a structured questionnaire was applied, which permits the analysis of the variable conditions according to the abortion intention, as per the proposed classification by the World Health Organization.

Results: The profile of the pregnant adolescents in the research work was: average age 16.1 years of age; with a stable partner; they are mullatos; they did not use any preservatives during sexual intercourse; with an average of 15 years old for the beginning of their sexual activities; they did not plan their gestation; they actually desired the pregnancy; they had an average gestational age of 13.2 weeks. About the outcome of the pregnancy, considering the type of abortion: 1.99% were spontaneous abortion and 98.01% were provoked abortions according to data acquired from the World Health Organization's classification and criteria. From the above mentioned data, 81.59% were certainly provoked; 9.95% were probably provoked; 6.47% were possibly provoked. Embryo and maternal tissue in the anatomic pathological characteristics were 88.56% and 11.44% respectively. Amongst the certainly provoked abortions, there was one case of hydatid form spring. There were no uterine punctures or perforations nor blood transfusion, 98.51%, 95.52%, respectively.

Conclusions: Urgency is hereby recommended for the family planning strategic programmes due to the fact female adolescents are provoking abortion as means to stop unplanned pregnancy and for the lacking of compulsory measures to conduct anatomic pathological tests in the material resulting from the abortion exposing accessory damages. Bioethics, duly guided by orientating principles, and for being applied ethics, is a very useful area of knowledge for the reflections concerning the abortion problem in the most varied areas of knowledge, in order to achieve the minimum common denominator amidst the variety of existing tendencies in the subject matter. To ethically apply the bioethics of justice, as well as to respect autonomy and plurality, essential items for the exercising of citizenship, can be the missing link between the humanizing values which are learned in the socialization process and an instrument for the minimal guidelines of protection and assistance to adolescents and provide help to the professionals in the health area.

Keywords: Abortion, family planning, health education

4 Ethical Defenselessness of Alternative Medical Systems

Munir Massud

This thesis will be estimate the bioethical dimension of Alternative Medicine in the face of an extensive analysis of its historical antecedents, its foundations, its credibility (effectiveness) and plausibility. And, for comparison, conventional medicine is defined as well as highlighted, its plans, its philosophy, its evolution, the need for a nosology and facts that prove that it is a scientific profession.

This thesis will attempt to demonstrate the ethical defenselessness of alternative medical systems and almost all forms of so-called complementary therapies, with a broad argument that pervades large areas of knowledge.

Finally, it will defend the hypothesis that complementary and alternative medicine in the West represent a continuation, after the advent of scientific medicine, of the speculative trend, derived from systematic and charlatans, which reached its zenith in the eighteenth century, but continued to thrive in the following centuries, or derive, in the face of this trend, the acceptance of archaic forms of therapy fraught with strange metaphysical conceptions and practices based on them or merely products of fantasy.

Keywords: Alternative medicine, bioethics, medicine

5 Autonomy Versus Medical Paternalism: the Bioethical Profile From the Egress of the Laboratory of Experimental Surgery from the Medicine Course of UEPA

José Antônio Cordero da Silva

The ethics principles are formed by four basic principles of equal value, which are autonomy, beneficence, non-malfeasance and justice. Medicine, since it was his Hippocratic learned to overvalue beneficence and no maleficence, not equal value in supplementing the patient's autonomy, allowing the review of the health status of the patient is only opinion and responsibility of the physician. Currently in several foreign countries, that reality changed radically, where doctors jointly discuss with patients the best treatment option, however in Brazil, the population views the physician as a superior being endowed with sense and incomparable critic who always seeks the best patient, this opinion should always be respected, even if the patient is disregarded. Thus, this study aims to verify whether the graduates of medical school ex-trainees of the Laboratory of Experimental Surgery present a profile that most self-respecting autonomy and beneficence of their patients. Search and cross prospective, approved in committee on ethics at the University of the State of Pará. It was sent to 138 medical students who graduated from medicine UEPA, who were interns Laboratory of Experimental Surgery. We assessed whether they have a profile that values more the autonomy or beneficence of their patients. For this we used a research protocol consists of eight parts, containing identification, academic, questions about the doctor-patient relationship, the physician's profile, the stage at LCE / UEPA, researched opinion on the hide patient information and meaning autonomy and paternalism, behavioural questionnaire and four cases vignettes. Of the total sample, 50 (36.23%) answered the questionnaire completely proposed. Of these 28 (56%) were male and 22 (44%) were women, the mean age was 28.5 years, 24 (48%) had between 6 and 10 years after graduation, 34 (68%) and has expertise only two (4%) underwent post-graduate-sense. Regarding biotic principles, not malfeasance was identified as the most important and most relevant, however beneficence was considered the more applicable, with a relative neglect justice in relation to other principles. In four cases the responses vignettes showed a profile paternalistic, except the third case, however, the analysis examined realizes that in general those surveyed had a profile more paternalistic in

the situation experienced, showing that in many situations the immediate recovery of the press health status of the patient regardless of their opinion. Regarding the part of the questionnaire used to determine the profile of respondents, they showed a profile paternalistic, yet only five respondents (10%) had a score that showed that these more respected the autonomy of patients. By synthesizing all data analyzed in this study, one notices that the graduates of LCE /UEPA have a profile patronizing. This result was found again rectified through case vignettes employees where more than half of those surveyed would perform paternalistic behaviours with patients idealized setting aside the wishes of the patient regarding their health status.

Keywords: Autonomy, doctor-patient relationship, ethics and bioethics, paternalism

6 Choosing Where to Die by Students and Doctors: Human Values and Perception of a Dignified Death

Inês Motta de Morais

Death is the permanent cessation of life in the body, but with the technical and scientific advances in medicine, it has been able to extend it for an indefinite period, changing the view about it. That bioethical problem is accentuated by the fact that, nowadays, most people do not die at home, but at hostile hospital context and alone. Given this fact, it has been discussed what is dignified death, what are its defining attributes, if this concept can be explained by human values and what implications they could have in the choice of where anyone would like to die. This dissertation aims to contribute to this debate, seeking to understand how medicine students and physicians realize the dignified death, relating this perception with their values and the choice of the place where they would like to die. Two studies were performed in Porto Velho (Brazil). Study 1 gathered 200 medicine students, who answered the following instruments: Perception of Dignified Death Scale, Basic Value Survey and demographic questions. Results showed the psychometric adequacy (validity and reliability) of the measure of perception of dignified death, composed by six factors: maintaining hope and pleasure, good relationship with the health staff, physical and cognitive control, not to be a burden to others, good relationships with family and control of future. The participants' perception of dignified death was best explained by normative and interactive subfunctions, and this last mediated the relationship between the perception of dignified death and the place where they wished to die; their home was chosen by nearly three-quarters of them. Study 2 sought to replicate the previous one, introducing variables about the physicians' personal and work contexts. Participants were 223 randomly selected physicians, who answered the same measures of perception of dignified death and human values, including demographic and work indicators.

Results confirmed the importance of interactive and normative subfunctions to explain the perception of dignified death, especially the factors good relations with family and good relationships with the health staff. More than three quarters of participants chose home as the place where they would like to die, and this variable was explained by existence and suprapersonal subfunctions, mediated by cognitive and physical control and not be a burden to others factors, respectively. This factor correlated with personal stability (e.g., age, working time).

In conclusion, it was observed the importance of values to explain the perception of dignified death, and choice of the place where medicine students and physicians would like to die, showing findings consistent with those of previous studies.

Keywords: Death and dying, medical ethics, medical teaching

7 Brazilian Medical Physicians and Students' Attitudes Towards Advance Directives

Mauro Brandão Carneiro

This thesis aimed to analyze the attitude of doctors and medical students in Brazil towards advance directives (ADs), based on the principles that guide the lives of these professionals and students. Three empirical studies were performed. *Study 1* aimed to develop a specific measure of attitudes toward ADs to represent two major attitudinal factors: *autonomy* and *paternalism*. This was a qualitative study, which sought to identify constitutive and operationally the two constructs and judges who assessed the instrument considered consensually that the Scale of Attitudes about Advance Directive (Escala de Atitudes frente às Diretivas Antecipadas de Vontade – EADAV) adequately represented the two factors. The scale was used in two subsequent studies to identify the positions of participants. For *Study 2* (with students), the first hypothesis establishes the existence of two attitudinal factors (*autonomy* and *paternalism*) according the adopted model; the other two hypothesis would demonstrate the correlation between attitudes and values: autonomic attitudes to correlate with *excitement* values that those paternalistic with *normative* values. This study included 701 students (average of 24.3 years, 61.4% female). The results confirmed the bifactorial structure of the EADAV, representing the two bioethical dimensions and supporting hypothesis 1. The other two hypothesis were also confirmed: students who score higher in *excitement* values tend to approve *autonomic* attitudes (hypothesis 2), whereas those with higher score in *normative* values prefer *paternalistic* attitudes (hypothesis 3). *Study 3* aimed to replicate the findings of the Study 2 in physicians who work in regional of the Medical Council in Brazil and to compare their scores with students. In this study, 426 physicians participated (average of 53.7 years, 77.4% male). The three hypotheses were the same as the previous study, and all were confirmed. Finally, comparisons between the scores of participants in two studies revealed that doctors were more paternalistic than students were; hierarchical regression analyzes showed that students and physicians vary in their priorities about values and attitudes toward ADs. However, this variable is more influenced by their sex and age than the fact of being part of a sample group or another; more important, thee values are predominant contribution, statistically relevant, to explain such bioethical attitudinal dimensions. In conclusion, the objectives of this thesis were achieved, confirming the theoretical framework shared between bioethics and psychosocial theories.

Keywords: Advance directives, attitudes, autonomy, human values, paternalism

8 Teen Pregnancy: Ethical and Social Reflexion

José Hiran Gallo

This study deals with the question of Teen Pregnancy, which accounts for 30% of all births in Brazil and occurs in different levels in the Latin American countries as well as in the developed world. Despite the substantial bibliography on the subject, we felt the need to study Teen Pregnancy in Porto Velho, capital of the State of Rondônia, in the Eastern Amazon area due to its nosological and geographical characteristics, where the prevalence of teen deliveries is of 28,7%.

The basis for this study was a transversal study carried out by the Hospital de Base Obstetrics Center in Porto Velho, Rondônia, Brazil, and all the relevant data from hospital records on the 4.710 births that occurred in the years of 2006 and 2007 were compiled. Field work took place in the county of Porto Velho, including a structured questionnaire and interviews with 422 adolescents who, at that time, had given birth to children at the Hospital de Base Obstetrics Center in the years of 2006 and 2007 and who were found in the addresses registered in their respective hospital records. Data were digitalized in the SPSS 15 Program (Statistical Package for the Social Sciences), analyzed and compared with data from related literature, in special those related to wishes, perceptions and expectations of the population studied.

We decided to include in the study all girls between 10 and 19 years of age, according to the World Health Organization (WHO), that defines youth as a period between 15 and 25 years old and adolescence from 10 to 19 years old. However, this parameter should be reconsidered, since there is a notable physical and emotional gradient between a 10-yearold girl and a 19-year-old girl, although both have the total dependence on third parties as a characteristic. This life phase can be defined as a period of great biological, social and psychological changes, subject to great vulnerability and, therefore, to risks.

The new affective relationships and the onset of the adolescents' sexual life are important milestones in their lives and the vulnerability of their bodies, still being development, become risk factors for teen pregnancy, which are related mainly with unfavourable socioeconomic conditions. Many are the reasons why these adolescents get pregnant: gender-intrinsic vulnerability, the special condition of being adolescent, life uncertainties, lack of future perspectives, the inadequate use of birth control methods, media influence, soap operas and Internet, a powerful tool, which has been incorporated in our lives, and, for many adolescents, the first and main source of information on their sexuality.

If the inclusion of technological resources in the practice of obstetrics has minimized obstetrics risks , the social risks still remain at extremely high levels, once pregnant teens still cannot carry on with their studies, find jobs and are more subject to mental disorders and more susceptible to STD and AIDS contamination. Teen pregnancy prevention measures are being widely discussed in the literature and, in general, have had little impact on preventing new pregnancies, especially because they are not attending the school, the ideal place for these interventions to occur. Newborn low weight was not verified in babies born to adolescents; however, neonatal mortality was significantly higher in teen pregnancies. A little less than 20% of the girls declared being happy during the interview, which made us believe that the problem of teen pregnancy must be dealt with carefully, both from the individual or the Public Health standpoint. Not only the incidence but also the recurrence of pregnancy and its consequences justify the great concern and continuous reflection of health sectors and their professionals, who, in a multidisciplinary joint effort, could sensitize all the actors involved towards a primordial prevention, promoting positive prevention factors to modify the always sad and unhappy future of these young mothers.

Keywords: Adolescence, perspectives, pregnancy, society, vulnerability

9 The Autonomy of Pregnant Woman and the Right to Request a C-Section

José Odair Ferrari

This work discusses the increasing incidence of elective c-sections in Latin American countries and around the developed world, which has motivated necessary and heated discussions in the field of Professional Ethics and Bioethics. A defense is made for the Right of the pregnant woman to decide between a vaginal and abdominal delivery, based on Principled Bioethics, and, in special, on the Autonomy Principle, giving her the autonomy to decide over her own body. A bibliographic review of international literature shows that, contrary to official guidelines, a vaginal birth - which is unquestionably more natural - pose risks that do not justify it as the norm, an authoritarian rule for pregnant women that look for public maternity wards in Brazil and are forced to give birth vaginally since it is the routine imposed by the services bureaucracy. Pregnant women can have personal motivations, fears, doubts and other reasons to refuse a vaginal delivery, but, in Brazil, these feelings are disrespected and the Right to choose for another type of delivery is denied. Poor women are forced to have children vaginally, while women with financial resources can choose a c-section since they can pay for the procedure. The Charity Principle motivates the study of the risks and benefits involved in the procedure for all involved: mother and new born. The literature presents uncontestable controversies in relation to these subjects. Meta-analytical studies are inconclusive and do not define clearly the risk and benefit relationship for this or that type of delivery, leading to wrong and ideological interpretations. The Principle of Justice that deals with the equal rights for users of health systems is also taken into consideration in this study as well as the approach related to the cost of each procedure. In the introductory pages of this doctoral thesis, a broad discussion on the increasing number of c-sections and on the role of delivery caretakers in this high index is presented. The research was based on a transversal study carried out at the Hospital de Base Obstetrics Center of Porto Velho, Rondônia, Brazil, using all the relevant data from medical records from 2006 to 2007. The field work took place in the county of Porto Velho, and a structured questionnaire was developed and applied to 1.261 women who had children at the referred hospital during that period, and who were found at the addresses registered in their medical records. Data were digitalized in the SPSS 15 (Statistical Package for the Social Sciences) program, analyzed and 10 compared with the data from related literature, in special those related to the desires and perceptions of pregnant women. Data and results are not different from those found in the literature that deal with the characteristics, desires and perceptions of women from other parts of the planet who carry human beings in their wombs to perpetuate human species. The literature has been, until now, controversial and does not reduce the conflicts and differences of opinion, so that the Charity Principle does not justify an only and universal position in relation to the way babies should be born. The Justice Principle, which deals with an equalitarian distribution of resources is not mandatory since many gaps still remain when the costs for each procedure is evaluated from the Public Health standpoint. Final results highlight the first principle in Principled Bioethics: the Autonomy which emancipates human reason, and enables the person to self-govern, think, evaluate, decide and act. The Autonomy is a prerequisite for any person's dignity and for his individual self-fulfillment. Autonomy must be carried out with knowledge, and choices must be made without any external influence and based on transparent, clear and true information provided by responsible and committed professionals, who have the obligation to help pregnant women make competent decisions, without hindering and diminishing her capacity to decide. The physician must be a partner, a confidant who cares for the well being of the patient. This doctoral thesis is an intransigent defense of Human Dignity.

Keywords: Beneficence, cesarean section, personal autonomy, social justice, vaginal delivery

10 Bioethical and Deontological Reflexion Related to Ethical and Disciplinary Reports and Legal Processes Involving Pediatricians in the State of São Paulo – Brazil

Clóvis Francisco Constantino

Research Hypothesis: The graduation in medical schools and the post-graduated medical training, as well as pediatric care in public institutions are determining factors in the probability of ethical and professional reports and processes.

Objectives: The main objective is to characterize and discuss, in the context of the State of São Paulo, Brazil, the specificities related to pediatric care from the standpoint of deontology and bioethics, relating them to the time of graduation, gender of the doctor involved, age, public or private nature of the training school, public or private nature of the workplace, as well as continued education related to the association with scientific expertise society. As a secondary objective, determine the causes of the complaints and ethical-professional processes and, if the lack of adequate training, both at the graduation and post-graduation associates with ethical and professional failures. Be able to demonstrate that the failure of graduation and continuing education are associated with medical failures. Discuss the doctor's error and the malpractice.

Methods: A retrospective and descriptive research with quantitative and qualitative design in the universe of 181 ethical and disciplinary proceedings in the period from 2001 to 2010 in a total of 247 doctors sued for children consultation under the Regional Council of Medicine of São Paulo (Conselho Regional de Medicina do Estado de São Paulo – CREMESP). The number of physicians is greater than the processes because there are processes with more than one physician. It was quantified those who had Specialist degrees in Pediatrics or Medical Residency. It was also quantified those that remained associated with the Brazilian Society of Pediatrics/São Paulo Pediatric Society (Sociedade Brasileira de Pediatria/Sociedade de Pediatria de São Paulo – SBP/SPSP) in the time of the survey. There were no exclusion criteria and not all procedures were completed at the end of data collection. Among the 247 physicians processed, 133 had already been submitted to the judgment at first instance and are included in their search results. Analyzes of statistical significance were done in several of the correlations with the chi-square calculation, the value of p and Fischer's exact test.

Results: Mostly men are involved (67.21%), 41.30% aged from 30 to 49, 57.89% aged 50 or older; 70.45% have 20 or more years of graduation; 42.51% graduated in schools of the State of São Paulo; equally, 42.51% graduated in private schools, 35.22% in public and 6.38% abroad, with no information about 15.79% . Of the ten (10) schools more related to complaints among the 57 quoted in the period, 61.39% are private. There were sixteen (16) citations of schools abroad, and all of them in South America. Among the care institutions where the facts were generated, 63.65% are public [Public Health System (Sistema Único de Saúde – SUS)]. Upstate, 73.2% occurred in the public sector and, when calculating capital and greater Sao Paulo, 54.3% was the percentage of the public. 67.40% were related to hospital care. 65.59% of the doctors had not related specialty in Pediatrics. 80.97% were not associated with Brazilian Society of Pediatrics/ São Paulo Pediatric Society (Sociedade Brasileira de Pediatria/Sociedade de Pediatria de São Paulo – SBP/SPSP). Of 247 physicians listed, 133 had already been tried, and acquitted 79 and 54 inmates. Of these, 83.33% had minor confidential penalties. The articles of the Code of Ethics involved prevalently were the numbers 29 and 57 in force at the time of the facts and relate to malpractice because their normative commands refer to incompetence, recklessness and negligence, the modalities of guilt.

Conclusions: Residency and Specialist degree are not legal prerequisites for the occupation, but they are critical for proper training in the practice of the specialty. Keeping associated with specialty society may mean less involvement in professional ethical problems. Graduation and inadequate continued education are insufficient in determining causes of complaints. Medical care in public institutions implies higher risk of ethical and disciplinary demands and hospital care prevails in the event of problems investigated.

Keywords: Bioethics, education, graduate, residency, medical ethics, medical malpractice, pediatrics

11 Ethical Issues Experienced by Nurses and Physicians in Primary Health Care

Ana Maria de Oliveira

Ethical issues occurring in Health Primary Care (PC) are frequent, subtle and are part of everyday routine. The interface with the human values is still incipient in Clinical Bioethics, although these values are principles that guide human actions and express their basic needs (biological, survival and social interaction).

An organized review on Bioethics and PC, from 2003 to 2012, revealed, among the little literature, an instrument of perception of ethical conflicts nominated Inventory of Ethical Problems in Primary Care IPE-APS, created by Zoboli & Silva. Two empirical ex post facto studies with non probabilistic samples were done with the aim of gathering psychometric evidence from the instrument, to explore the factorial structure, to confirm the factorial congruence of measurement and to relate with the Value Correlates. Study 1 involved 88 doctors and nurses from Primary Family Health Centers (PFHC) of three cities in the metropolitan region of Goiânia, Goiás, Brazil, who answered the IPE-APS, an another questionnaire about basic values, sociodemographic and labor profiles. From the participants, most were females (83%), married (58%) and catholic (68%).

As for the results and discussion, it was proved the validity and accuracy of the IPE-APS adapted with 25 Items, compounded by Factor I (Cronbach's Alpha = 0.92) and Factor II (Cronbach's Alpha = 0.90), respectively with 14 and 11 items. The IPE-APS items belonging to Factor I (affectivity / accountability) are related to Deontology and Human Rights, and Factor II, to Structure of labor. The Study 2 was made with 207 professionals, 90 doctors (43.5%) and 117 nurses (56.5%) from PFHC of Goiânia. Most of participants were female (79.2%), married (58.5%) and catholic (55.1%). It turned out that the Factor I demonstrated high Congruence Factor Index (0.98), which shows high similarity and expresses that the instrument has practical validity to identify and assess the perception of ethical issues in PC.

It was concluded that the studies will improve the quality of health care, including the teaching-learning process in ethics/ bioethics in professional practice. Based on the Functionalist Theory of Human Values there was a convergent standard at the suprapersonal-interactive-existence axis that superimposes both professionals, meaning a profile that supports the need for love and social belonging, relationships and the sharing of care and sorrow.

Keywords: Medical teaching, primary care, universal healthcare

12 The Moral Judgement Competence Among Medical Students: a Transcultural Study

Helvécio Neves Feitosa

Introduction: The moral judgment competence or moral maturity was defined by Lawrence Kohlberg as "the capacity to make decisions and judgments which are moral (that is, based on internal principles) and to act in accordance with such judgments" (Kohlberg 1964, p.425). Thus, morality is an aspect of capacity and therefore should not be given attention only in its affective aspect. However, the affective bond with the ideals and moral principles most likely represent a condition for morality developed. Morality is based on internal principles and only then, by his own personal commitment to moral ideals can support democratic important capabilities such as autonomy and maturity. As seen, the action is part of the definition, that is, morality can't be limited to ideals and values but must be manifested in behaviour, before one can speak of moral capacities. It is considered that morality, democracy and education are closely linked. Modern democracies rely on the idea that people living in a society is governed by themselves, based on moral principles, with which all are committed. In this context, the study of the morality of medical students seems extremely relevant, since after a diagnosis of positive or negative curriculum influence on the moral development of students, we can take strategize to maintain the status quo or to correct course, to objectify a qualified professional exercise in the future.

Objectives: Determine the moral judgment competence (C-score), moral attitudes and opinions as to analyze the solutions of the MJT dilemmas among students of the first and eighth semester of the two institutions. Compare the classes of the first and eighth semester of each medical school regarding the parameters mentioned above and the corresponding classes of the two medical schools. Analyze the influence of factors such as age and gender on the C-score. Correlate C-scores with moral attitudes and opinions regarding solutions to dilemmas.

Materials and methods: We conducted a cross-sectional transcultural study, using the MJT, which was applied to groups of students of a medical school in the Northeast Region of Brazil and a medical school in the North Region of Portugal, in the first semester of 2011. The C-score calculation was done on an Excel spreadsheet, using a method analogous to the multivariate analysis of variance (MANOVA) that is, dividing the sum of squares in a range of 0 (zero) to 100. The phenomenon of "moral segmentation" was considered if occur statistically significant difference in C-scores between the two MJT dilemmas. We evaluated the influence of factors such as age (the same semester students in each school) and gender on the C-score. Moral attitudes were established by the sums of the preferences by the arguments for and against the decisions taken in each of the six stages of Kohlberg's moral reasoning for both dilemmas, in a range of -16 to + 16. For the students' opinion about the given solution to the MJT dilemmas was considered strong disagreement / agreement (-3 or +3), moderate disagreement / agreement (-2, -1 or +1, +2), no agreement and no disagreement (0). The statistical tests used were ANOVA, Wilcoxon test, logistic regression, Mann-Whitney test, Pearson's linear correlation, Fisher's exact test, Bonferroni test and Student's t test, depending on the nature of the comparison. Considered the significance level of p 5 points (absolute effect-size) were also considered significant and differences in C-scores >10 points very significant (Schillinger 2006).

Results: This study showed regression of moral judgment competence between the eighth semester students against the first semester students of a Brazilian medical school and stagnation of moral competence between the corresponding classes of Portuguese medical school ($p = 0.06$). The Portuguese medical students had higher C-scores than the Brazilian medical students for both, the first ($p = 0.008$) and the eighth semester. In the analysis of student performance by MJT dilemmas, it was observed the phenomenon of "moral segmentation" in all classes, that is, students had better performance to the worker's dilemma in relation to the doctor's dilemma. Students with older age in the same class had lower levels of C-score. There was no significant difference between men and women regarding the C-score and performance by dilemmas. In assessing the preference for arguments (attitudes) of the six Kohlberg's moral stages, it was observed similar behaviour among all classes, with a strong rejection of the pre-conventional level arguments (stages 1 and 2) and strong acceptance of the post-conventional level arguments (stages 5 and 6), with a predominance of poor acceptance of the conventional level arguments (stages 3 and 4). There was observed the affective-cognitive parallelism, in which students with higher C-score rejected the arguments of the preconventional level more intensely and accepted more intensively on the post-conventional level. There was a higher preference for the stage 5 arguments to the worker's dilemma and for the stage 6 arguments to doctor's dilemma in all classes. In the analysis of the students' opinion on the resolution given to the MJT dilemmas, it was observed that for the worker's dilemma predominated moderate disagreement

(-2, -1), and for the doctor's dilemma predominated moderate agreement (+1, +2). Brazilian students tended to show disagreement of greater intensity than Portuguese students for both dilemmas did. There was a correlation between low C score and intense disagreement (-3) for both dilemmas in most classes.

Conclusions: The pedagogical model of undergraduate medical teaching in the years preceding the medical internship was not effective in promoting the development of moral judgment competence of students. In contrast, there was regression or at least stagnation of such competence. Portuguese students tended to have higher C-score than the Brazilians did. The age factor had higher negative influence on moral competence, while gender did not influence. The phenomenon of "moral segmentation" was observed in both medical schools with better student performance to the worker's dilemma in relation to the doctor's dilemma. There was observed affective-cognitive parallelism, because students with higher C-scores showed more intense rejection of the arguments of the Kohlberg's pre-conventional level and stronger acceptance of arguments to the post-conventional level. Extreme views of denial regarding the solutions given to the MJT moral dilemmas were correlated with moral judgment competence lower. The finding that occur regression or stagnation of moral judgment competence in undergraduate medical course deserves thorough consideration to that deal with political and pedagogical projects of Medicine courses and the entire medical faculty, in order to reassess and implement curricular strategies that work adequately addressed the students moral development.

Keywords: Medical education, medical students, moral development, moral judgment competence, moral judgment test, undergraduate medical education

13 Dignified Death and the Place to Die

Maria do Carmo Demasi Wansa

The world has witnessed an extraordinary advance in science and technology, reflecting in more longevity of population. In face of technicality, it's discussed the humanization of care with oncological patients, attending to their last will of dying with dignity. This imposes the need to consider their preference regarding the place where would like to die, guaranteeing a good death. In this mark, the present dissertation is inserted, which aims at knowing people preference (general population, oncological patients and their families) is regarding the place where they wish to die, trying to explain it from their values and perception of dignified death.

Two studies were conducted. Study 1 gathered 200 participants from general population, who answered the Perception of Good Death Scale, the Basic Value Survey and demographic questions. Results showed adequate psychometric parameters (evidences of validity and reliability) of the briefed measure of perception of good death, composed by six factors: maintaining hope and pleasure, good relationship with the health professional staff, physical and cognitive control, not being a burden to others, good relationship with family, and control of future. Value subfunctions interactive and suprapersonal explained the perception of good death, and the suprapersonal mediated the relation between this perception and the preference for dying at home.

Moreover, mostly people expressed the desire of dying at home. Study 2 consisted of 200 people equally distributed into oncological patients and their families, who answered the three instruments: briefed measure of perception of good death, human values and demographic questions. Results indicated that, for both oncological patients and their families, two value subfunctions (excitement and normative) explained directly the perception of good death. Regarding the place where they would like to die, patients with higher scores in excitement indicated less preference for dying at home.

Finally, the oncological patients preferred dying at home, being this preference higher than that of their families. These findings were consistent with those observed in other Latin countries, suggesting that the dignity of death is perceived as an opportunity to die in a family milieu, particularly for those who prioritize less personal values.

Keywords: Death and dying, medical ethics, medical training

14 The Quality of Life in Deaf Children and Adolescents with Cochlear Implant

Ivone Maria Resende Figueiredo Duarte

Background: Deafness is currently considered a huge social problem not only because of its prevalence but also due to the multiple consequences that entails under various angles. It interferes permanently in child development. Interferes permanently in the development of verbal and language skills of children and their quality of life, leading to learning difficulties and deleterious effects on social, emotional, cognitive and academic performance.

It's clear today that cochlear implants are an important treatment modality for profoundly deaf children. It's finally possible to successfully overcome a handicap in one of the special senses of the human kind. Cochlear implant technology has been characterized by some as an attack on the culture of the deaf and socio-cultural genocide. Many are the bioethical controversies around cochlear implants, as representatives from the Deaf World have seen in them a means of decimating their culture and intrinsic values.

For an easier context of this work, we discuss at first the different perspectives of deafness, specifically deafness as a disease, disability and difference; in a second part we present our studies undertaken in this area.

The objectives of the three studies in the present thesis were: a) to determine the quality of life related to health in the perspective of children and adolescents with cochlear implants compared with their peers without implants and hearing, as well as determining the quality of life associated with health in the perspective of their parents; b) To evaluate the impact of cochlear implants on the school failure of deaf who attend mainstream classes by comparing them to their normal-hearing peers as well as deaf without cochlear implants and family participation in school life; and finally c) to study the number of cochlear implants in children and adolescents conducted in different regions of mainland Portugal and determine the percentage of cochlear implants performed at early ages.

Methods: The first study was a cross-sectional study that included three groups: prelingual implanted deaf children and adolescents; prelingual deaf children and adolescents without implants; and normal-hearing children and adolescents. All included subjects aged between 8 and 18 years and attended school in Portugal. Parents and children/adolescents were surveyed using the Kidscreen-52, which is a generic instrument for assessing the health related quality of life of children and adolescents. Structured interviews were conducted with parents to collect information and clinical histories, and the Graffar scale was used to assess socioeconomic status.

The second study was a case-control study included participants aged 8 to 18 years, using 24 children and adolescents with cochlear implants, 24 children and adolescents without cochlear implants, and 24 normal-hearing children and adolescents aged 8 to 18 years, attending school in Portugal. Each student was matched by gender and age. The data collection was performed by teachers, who used school records and completed a short questionnaire regarding parent participation in each student's school life. We also administered a semi-structured interview to the parents to collect a clinical history and sociodemographic data so that the Graffar Scale could be used to assess socioeconomic status.

The third study was a retrospective study of cochlear implantation was conducted using a hospital data base containing all the episodes with cochlear implant procedures in public hospitals that occurred in Portugal between 2000 and 2012. An analysis by age, year and region of the implants was performed.

Results: In the first study, the hearing participants had significant better quality of life than not implanted deaf participants in almost all domains did. On the other hand, although hearing participants also had slightly better quality of life than implanted deaf children these differences were lower and not significant. Similar trends were observed among the responses of deaf children and their parents.

In the second study, we found that the greatest differences in achievement levels were found between hearing students and those who were deaf without cochlear implants. We found that cochlear-implanted deaf participants repeated fewer grades than deaf children without implants. We also found that the teachers believed that, parents of non-implanted deaf participants provided less homework support to their deaf children than the parents of deaf children with cochlear implants.

In the third study we found that the Northern and Central regions, the nearest big center specializing in cochlear implants in Portugal, are those with the largest number of implants, 2.0 and 2.4 per 10,000 children respectively, and the regions of Alentejo and Algarve, more rural regions and distant from the center, which records the smallest number of implants, 1.1 and 1.5 per 10,000 children. Although over

the years there seems to be an increase of children, under 18 implemented, verifying a significant reduction in 2011 and 2012. However, it has been observed an increase in children implanted before 24 months, from the same zero children at this age in the early years studied to 0.46 per 10,000 inhabitants in 2012.

Conclusions: Deafness can be considered as an aggravating factor in school performance and perception of quality of life. Cochlear implantation seems to minimize the differences found between deaf and hearing children. The right to adequate health care must be in accordance with the full respect of fundamental human rights. Economic, social and educational conditions must also be guaranteed in this process of auditory rehabilitation. Taking into consideration the results of this studies, it is an ethical imperative that Portugal promote appropriate policies both in health and education in order to ensure deaf children what they need for full development of their personality and thus respect the principle of equal opportunities.

Keywords: Cochlear implant, equal opportunities, justice

15 The Free, Prior and Informed Consent (FPIC) and the Humanization Process on the Medical Health Care: an Explanation Grounded in Human Values and Attitudes

Ângela Maria Moreira Canuto Mendonça

The intention of this study was to survey the beliefs and perspectives of medical students and medical professors about the understanding, use and importance of the FPIC and the Humanizing practice in medical health care. For this, it was conducted 3 specific studies: Study 1 aimed to describe the beliefs and perspectives of students and professors of medicine about the FPIC and the Humanization. Through software Alceste were performed computerized content analysis supported by statistical techniques of $\chi 2$ (coefficient of association) and Factorial Analysis of Correspondence; Study 2 aimed to develop a psychometric measure for identifying attitudes towards FPIC and Humanization, and were proceeded an Exploratory Factor Analysis and an application of the test of Cronbach's Alpha; And, Study 3 aimed to understand how human values and attitudes permeate and explain the beliefs of doctors about the FPIC and the Humanization in their professional practice. Through a comparative analysis in which were performed descriptive statistics (mean, standard deviation, standard error and confidence interval of 95%) and decision making (student t test) to compare the mean scores of the constructs considered in function of item-criterion and gender. As a result, were found some evidence that the participants understood the Informed Consent and its use in the humanization process. In addition, it was developed a measure theoretically grounded, empirically tested, and parsimonious in fact, which has 14 specific items. Furthermore, the study showed that women doctors tend to be more humanized, since there was a predominance of women among behavioural intent. Finally, it was found that the humanization has as predictors the constructs of Intent Behavioural (attitude) and Humanitarian and Social (human values), i.e., people who are not attached to material things and tend to give more importance to affections and pleasures of life, emphasizing interpersonal relationships, which may indicate that the humanization cannot be taught, but that is part of an idiosyncratic life of the individual, that is, can be born or even cultural.

Keywords: Bioethics, FPIC, humanization, medicine

16 Advance Directives for People with Dementia

Cláudia Burlá

The growth in world ageing is associated with an increase in life expectancy, particularly in persons of more advanced ages, which expands the number of older persons with chronic-degenerative diseases, Alzheimer's disease in particular. Such individuals require specialized treatment and care. They challenge medical practice because they present multidimensional health conditions, notably cognitive impairment, which irreversibly compromises their autonomy, one of the pillars of Bioethics.

In this context, this study was conducted so that, in proceeding with the search of theories, we could reflect on the loss of autonomy of the person with dementia, considering Advance Directives as an instrument providing protection and assurance that the person's wishes would be complied with in the future.

The methodology chosen was qualitative health research centered in a reflexive investigation, promoting a dialogue between biomedical facts and bioethical frameworks. For the review of literature, we examined to books and journals posted on PubMed and LILACS data bases over the past 10 years.

We have discussed the pertinence of Advance Directives as a successful construct of our civilization for prioritizing the autonomy of the individual and ensuring the full exercise of their rights as citizens. This instrument should be created by healthy older individuals prior to the development of cognitive impairment that may occur in keeping with demographic and epidemiological data. In the progressive course of dementia, even in its early stages, the recording of the person's wishes about what they want or not for themselves in terms of treatment an In the conclusion of our study, we propose that Geriatrics and Bioethics be connected, so that qualified practitioners could guide older people and their family in an in-depth reflection about health and disease, autonomy and impairment, so that they can make their wishes count in an uncertain future, when they may no longer be able to make this choice themselves.

Keywords: Ageing, Alzheimer's disease, autonomy, advance directives, dementia, living will, older people

17 Health Technology Assessment: a Bioethical Perspective

Ana Maria Pinto Saraiva

Developed societies are characterized by a decrease of infant mortality and an increase of expectancy, leading to population aging and consequently an increase in chronic and degenerative diseases. A steady supply of technological innovation in healthcare induces demand and costs. In an attempt to solve this problem, concepts such as technology assessment and rationing care based on various criteria, are identified as resolution assumptions, while ensuring equity in access and efficiency in outcomes. Based on this fact, we formulated as a research problem: "How do nurses perceive the decision to access health technology under the bioethical point of view?". We have defined as study objectives to identify and analyze the factors related to health policy and the ethical principles that may limit or not the decision to access health technology. The study carried out is a descriptive and exploratory type of study and the sample is non-probabilistic for convenience constituted of 506 nurses. Collected data used an opinion questionnaire based on a Likert Scale and consists of two dimensions: health policy and ethical principles and was validated using factor analysis. The collected data analysis was obtained using descriptive statistics, inferential statistics through non-parametric techniques and the association analysis between variables.

We concluded that nurses agree to universal access to care and the implicit rationing, based on the best interests of the patient, granted on charity and paternalism and without casuistic discrimination; they consider that technology assessment should be carried out in line with the results of its use at various levels; aspects related to the patient's survival must also be met to access that technology. They disagree with the explicit rationing and that access decision falls outside the relational framework. They have ambiguous concerning funding maintenance or its change.

They disagree that technology foments dysthanasia as well as the exercise of autonomy to use technology that has no applicability even if funded by itself. They agree with the prevalence of individual welfare over the common good and to continue to "give everything to everyone" (underlying principle of our National Health Service practice).

Keywords: Age, ethical principles, health policy, health technology, rationing

18 Bioethical Analysis of Complaints against Physicians at the Regional Medical Council of the State of Acre

Dilza T. Ambros Ribeiro

The activity of the medical professional is regulated by the code of medical ethics which, guarantees the patients' rights, and gives guidelines for what should be done when the doctor does not act in accordance with ethical principles. In this sense, the present thesis has the main objective of to build a profile of the doctors denounced to the Regional Medical Council of Acre, for violations of the ethical precepts. Therefore, the present thesis was divided in two parts. The first part has four chapters that seek to define a theoretical framework. The first chapter presents an introduction on bioethics, professional activity of medicine and regulatory councils. The second chapter seeks to review the causes of medical errors. The third chapter analyzes the influence of medical faculties abroad on the practice of medicine in the State of Acre. Finally, the fourth chapter deals with the influence of medical schools abroad on the practice of medicine in the State of Acre. The second part of the thesis presents an empirical research survey. In order to do so, 121 complaints were filed against physicians determined by the Regional Council of Medicine of Acre between 1993 and 2009. The objectives of the research were to make a distinction about the activity of foreign and Brazilian physicians in the state of Acre and to make a survey of the areas of medical specialties in which the highest index of complaints occurred in the Regional Council of Medicine of this state. The results indicate that more errors are made by Brazilians, followed by foreign doctors from countries bordering Acre, Peru and Bolivia. They also point out that the specialties most susceptible to "medical errors" were the General Practice and Gynecology. Analyzing the two parts together, it is concluded that the present thesis has merits in drawing a profile of the complaints against physicians in the state of Acre, analyzed in light of the bioethical principles and guidelines of the profession taken into account in the theoretical framework. These data may be used in the future by the health secretariats with the purpose of introducing changes that seek to reduce the number of complaints against physicians working in Acre.

Keywords: Bioethics, complaints, medical error, Regional Council of Medicine of Acre, specialties

19 Threat to the Bioethical Principles in Medical Practice: Two Decades of Ethical-Professional Processes in Brazil (1988-2010)

Giselle Gracindo

The medical ethics code aims to ensure that doctors have absolute respect for their patients and always act towards benefiting them, while avoiding causing them any physical or mental distress and ensuring their integrity and dignity. Despite these fundamental principles, the number of cases of violations of the ethical precepts of medicine has been increasing year by year. In this light, the present doctoral thesis had the aim of outlining the profile of medical professionals in Brazil who violated the bioethics principles set forth in the ethics code of this profession and were judged at the Higher Court of Medical Ethics between 2010 and 2016. This thesis is divided into two parts. The first part establishes some theoretical markers regarding the main bioethical principles found in the literature, i.e. doing no harm, providing benefit and remaining autonomous; and presents the characteristics of the medical profession, with clarifications regarding its functions, specialties and attributes. The second part presents an empirical study in article format, consisting of a survey in which the database of professional ethics cases extracted from plenary sessions of the medical ethics court (TSEM) of the Federal Medical Council was used. These were disciplinary ethics cases that were judged at appeal level between 2010 and 2016, which were designated either as appeals (RPEP) or referrals (REMPEP). The results showed that most of these professionals were male (88.5%), with a mean age of 59.9 years (SD = 11.62) when the appeal was judged, ranging from 28 to 95 years. The largest proportion of them was working in the southeastern region (50.89%). Articles 1 and 18 of the medical ethics code were the ones most frequently infringed. The most frequent punishment consisted of striking them off the register (37.6%) and the acts that were most often punished involved malpractice, imprudence and negligence (18.49%). From the theoretical markers produced in the first part of this thesis and the empirical study developed in the second part, it can be concluded that concern for the principles of bioethics is present in the decisions from appeals heard in plenary sessions of the TSEM of the Federal Medical Council, and that the principles of doing no harm, providing benefit and remaining autonomous have been incorporated into the set of articles of the new medical ethics code of 2009, which governs the profession.

Keywords: Bioethics, ethics codes, medical ethics, principles

20 Bioethical Dilemmas, Stress and Quality of Life in Community Health Workers

Ulysses Castro

This work took into consideration the issue of bioethics in health, and of the ethical and moral conduct of health professionals, along the issue of those assisted by the primary health care programs in Brazil, with the intent of improving both the working conditions and the healthcare conditions of patients assisted in the mental health field. Moreover, the present research proposed the investigation, in stages, of the mental condition under which lie the Community Health Workers (CHW) in two satellite cities of Brasilia, in an attempt to identify measures to solve problems related to ethical conflicts in the professional practice of the CHWs matrixed in mental health. To achieve that goal, a sample was used throughout the development of the thesis consisting of 97 CHWs who were being matrixed in mental health of the regional health care in regions Riacho Fundo I and II in Distrito Federal, Brazil. The inclusion criteria was having participated in the mental health matrixing. No participant was excluded from the sample. Regarding ethical considerations, the scales were applied in December 2012, in a private room on the premises of the health centers. The project was approved by the ethics committee of FEPECS / SES / DF under No. 643/11, on 15/02/2012. Throughout the thesis, evaluative instruments were developed and applied. Among the instruments used are the SWS Survey and the WHOQOL-100, besides the questionnaire developed to be validated. As data analyzes, analyzes of variance, means tests, frequency analyzes, Cronbach's Alpha analzsis, Pearson's correlation and canonical correlation were used, among other descriptive analyzes, to extract the results, serving as a basis for discussions and conclusions. Data were analyzed using SPSS (version 19 for Windows). For all tests, the value of $p < 0.05$ was assumed as the critical value of significance. Sociodemographic data of the 97 CWHs revealed that the majority was of women (78.4%). The age of almost half of the group falls in the age group of 30-39 years (40.2%); 51% of respondents were married. Of respondents, it was observed that 57.7% have average socioeconomic status. The group is divided between those who do basic (55.7%) or average (41.2%) work. The education of the majority of the group is completed high school (47.4%), but there are individuals with a college degree (23.7%). The majority of agents works 40 hours per week (97.9%) in the morning/afternoon shift (96.9%). Most of these workers had about 7 years of service at the time of the survey. In the second chapter, the research identified bioethical conflicts between the principles of justice and equity, autonomy and vulnerability of these actors in the mental health care of the assisted population. There is a need for promotion, training and qualification in the matricial process in mental health of health workers, so that they exercise their role as partners in transforming actions in primary care. In the next chapter, which intended to check the reliability of a questionnaire for evaluating the working conditions of the CHWs, the Cronbach's Alpha value was of 0.76, meeting standards established as reliable, which suggests that the coefficients values should be greater than 0.7 to be reliable. In the chapter on perception of threat and frequency in the everyday of the CHWs, it was found that CHWs' judgments corresponded predominantly to the midrange in the scale of responses. In that sense, the most frequent responses to the occurrence in practice and threat perception were "sometimes" or "often". The results showed that most of the judgments of occurrence and threat perception are positively correlated, with eight associations displaying medium strength and five weak associations. Only three correlations were not statistically significant. The results on the question of stress in CHWs revealed that all stressing factors are negatively correlated with the factors of mental health (mean values of correlation of -0.58 between variables), that is, the higher the stress, the lower the rates of mental health are. The correlations also show that stress levels are positively associated, indicating that the higher an indicator of stress, the higher any indicator in this category will be. The mental health indicators are also strongly and positively associated (mean = 0.71, SD = 0.04), indicating that individuals with higher rates of mental health reveal more personal, social and work support. Regarding quality of life, an analysis of the mean values obtained for each WHOQOL question showed that the CHWs tended to opt for an average judgment in the scale. Sociodemographic variables are associated with significant differences between the means in some domains. In the domains "social relationships" and "environment", means between men and women were significantly different. The socioeconomic level of the CHWs was also associated with significant differences in the level of independence. Concerning mental health and psychosocial risk factors in relation to quality of life, the results suggested that several stress-inducing factors among community health workers might cause a loss in quality of life. There was a trend that the better the environment, the higher the level of independence, and, the better the social relations of the CHWs, the lower the stress in their work.

Keywords: Bioethics, bioethics of protection, community health workers, quality of life, work stress

21 Ethics and Moral Competence of Medical and Nursing Students

Vera Sílvia Meireles Martins

Introduction: We live in an era marked by the development of increasingly innovative treatments in healthcare and the need for the health professional to respond to innumerable ethical dilemmas in clinical practice, demonstrating competence to make decisions. In view of the world´s constant technological advances, a profound reflection on the curricular strategies to be implemented in order to develop the moral competence of medical and nursing students is extremely relevant.

Objectives: The objectives of the four studies presented in this thesis were: a) to determine and compare the level of moral competence of medical and nursing students; b) to determine whether the Bioethics teaching can influence students' moral competence and opinion; c) to investigate the level of influence that the Bioethics teaching has in the decision making of medical students; d) to reflect on the development of moral and professional competence in nursing students, presenting the link between the ethics teaching and the moral and professional competence of nursing students and suggesting strategies that promote the moral competence of nursing students.

Methods: In the first three articles presented, longitudinal and descriptive studies were carried out, which consisted of applying the Moral Competence Test extended questionnaire (MCTxt) to medical and nursing students in Portugal. In the first study, the questionnaire was applied to medical students from three medical schools and nursing students from three nursing schools in the North and Center of Portugal. In the second study the questionnaire was applied to nursing students at a nursing school and in the third study the questionnaire was applied to medical students at a medical school. The questionnaire was applied before and after the Ethics curricular unit, in the second semester of 2018. Through its application it was possible to determine the moral competence and the opinion of the students on the three moral dilemmas with which they were faced. The scores of opinion and moral competence were described using the mean and standard deviation and in the comparison of the scores in the two moments, the method of the t-test for paired samples was used. A multivariate analysis of linear regression was performed for each of the scores and a significance level of 5% was used. In the third article, changes in opinion between the first and second moments were described with the frequencies and percentages of students who changed their minds from the first to the second application of the questionnaire and their 95% confidence intervals. The fourth article is an opinion article in which strategies are proposed to increase the moral and professional competence of nursing students.

Results: In the first article, out of a total of 918 students enrolled in the Ethics course, 400 students duly filled out the questionnaire at both times, of which 104 medical students and 296 nursing students. Given the low response rate, data obtained in schools with a response rate above 50% are analyzed. It appears that for all students the average of the total score drops in the second moment, about 1.5 points in nursing students and 1.2 points in medical students. Medical students have higher moral competence values than nursing students, although the difference is not significant. In a multivariate analysis, this decrease does not seem to be related to either sex (b= 1.623 p = 0.415), nor to the course (b = 1.111 p = 0.566), nor to age (b = 0.272 p = 0.269). In the second article, of a total of 135 students enrolled in the curricular unit of Bioethics and Ethics in Nursing, 122 questionnaires were filled in the two moments. It´s aparent that students have lower total C score values in the second moment of application of the questionnaire (21.5 points) in relation to the first moment (22.7 points), revealing a moral stagnation. The students present an opinion that is in agreement with the performance of the doctor and the judge and not in agreement with the performance of the worker in the second moment of application of the questionnaire. No statistical association was found between the age of the students and the changes between the first and the second moment of application of the questionnaire in the total score values (spearman's rho = -0.106; p = 0.245). In female students (n = 107) there is an average decrease of 0.67 (standard deviation = 11) in the total score and in male students (n = 15) there is an average increase of 5.04 (standard deviation = 15), however this difference is not significant (p = 0.187). In the third study of a total of 125 students who were enrolled in the curricular unit of Bioethics and Medical Deontology, 70 (56%) medical students duly completed the questionnaire at both times.

It was possible to verify that the students presented disagreement with the performance of the characters in the dilemma of the worker at both times and agreement with the behavior of the doctor and the judge in the two moments of application of the questionnaire. There are no significant differences, in the students' opinion, between the two moments of application of the questionnaire, although there is a trend towards greater agreement in the second moment. It is also noted that for all students who were neutral

at the first moment, the majority decided that either agreed or disagreed with the performance of the characters in the second moment of application of the questionnaire. In the fourth article through bibliographic research it is possible to verify that several authors suggest that ethics has an important role in the development of moral competence.

Discussion: The results presented indicate that students after attending the Ethics course show a decrease in moral competence score, corresponding to moral stagnation. This tendency towards a decrease in the moral competence scores is already mentioned in several studies related to the moral competence of medical and nursing students. Regarding the opinion of medical students, there is a greater confidence on the part of students who were neutral at first, to make a decision that agrees or disagree with the performance of the characters after attending this course.

Conclusion: This thesis results have showed that there is a need to develop strategies that promote the development of moral competence, such as the introduction of the teaching of ethics at other levels of education, the use of methods and methodologies that promote the development of moral competence, the teaching of ethics before and after experience in the clinical environment, the example given by clinical teaching tutors who are models of good ethical practices and an environment learning that promotes reflection and critical judgment.

Keywords: Ethics, medicine, moral competence, nursing, students

22 The Right to Be Forgotten Regarding Health Data

Mónica Maria Bessa Correia

In the context of technological developments in recent years, massive data collection is widespread throughout society. The so-called *big data* era is problematic due to the interface between *big data* and robotics, artificial intelligence and quantum computing, which allow the communication of data related to human beings to others for a wide range of purposes such as, for example, the measurement, registry and analysis of health information. Large volumes of data challenge some of the fundamental principles of privacy: self-determination, minimisation of data collection, informed consent and the right of individual access. The challenge of privacy in this context is, above all, that of informational privacy.

At present, privacy is more demanding regarding health data and, above all, genetic data, given their extreme sensitiveness. Other pressing issues today are gender identity, whether or not gametes donors' identity should be disclosed in medically assisted reproduction, and digital surveillance to gather individual health information due to public health emergencies. To ensure an adequate level of privacy requires a careful ethical analysis of the configuration of legal rules to safeguard the value of privacy and, ultimately, human dignity.

In the framework of loss of control over personal data, which encourages privacy violations, the so-called "right to be forgotten" recognised in the European Union General Data Protection Regulation (GDPR), i.e. the right to obtain from the controller the erasure of records/personal information, has been widely discussed, especially in Europe and the United States of America. The scientific literature on this new legal norm is still scarce. Although some studies provide relevant information on the topic, these perspectives do not raise the ethical issues associated with the possibility to delete health data in general and genetic data in particular.

By articulating the right to be forgotten with the ownership of health and genetic data and the values of privacy, identity, and autonomy, a new paradigm emerges. This articulation calls for a bioethics approach because the latter seeks to respond to new problems resulting from the changes brought about by new technologies in life sciences. In this sense, this thesis analyses the extent to which the right to be

forgotten regarding health data is ethically admissible. The specific objectives of this thesis explored: the principles of autonomy, privacy and human dignity concerning the right to have genetic data erased; the relationship between gender transition-related health data and privacy, data protection and identity projection; the ethical dilemma of identifying gametes donors in the case of medically assisted reproduction techniques (ART), and the relationship between privacy and health data when it comes to transmittable diseases, such as the COVID-19.

The thesis adopts the analysis of the leading international and national documents related to privacy and data protection to contextualise and frame the current understanding of privacy issues arising from health, especially in the interface with technology development. The relevance of using theoretical, ethical and legal research distinguishes the fundamental concepts and discourses that support the importance of privacy values in health and the need to protect the right to privacy in the future. Most contentious cases are comprised the specific objectives and are included in the analysis because they promote the development of theory, demonstrating, in a practical way, how health, technology, ethics and the law have an impact on the values that support fundamental rights.

This thesis includes seven chapters and integrates four original articles. Two of these articles were accepted for publication in international scientific journals with ISI impact factor, and the other two, submitted for publication in the same type of journals, are under peer-review process.

Regarding the right to have health data, in general, and genetic data in particular deleted, the research concluded that if this issue is not addressed adequately at the international level, it might have an unintended effect by the Member States that signed and gave binding force to the General Data Protection Regulation. This data may escape the provision of that Regulation, inclusively allowing undue erasure or elimination if this matter is not deepened. The admissibility of the right to be forgotten related to health and genetic data may threaten humanity's fundamental ethical values, with the risk of compromising human dignity, unless there is international law to ensure that health and genetic data are not erased, despite the imperative need for adequate protection of individual privacy rights.

Regarding gender transition, we found that an eventual right to have health data deleted must be limited and regulated. The recognition of gender identity as a fundamental human right – in the sense of the full development of an individual's personality through self-determination and self-realisation – is accepted as an integral part of respect for human dignity. However, the erasure of health data should be regulated at an international level to protect the human person's inalienable rights and future generations. The fundamental issue is the ethics that should inspire the regulation of this matter. Data that affects the right to self-determination of other individuals, present or future, cannot be subject to erasure, not even to a definitive obstruction through technological access. Gender identity is a fundamental value related to personality, but it must not prevail without considering other values because it should not be considered absolute. An ethical discussion is urgent about the specific characteristics of the right to have gender-affirming data deleted.

Regarding medically assisted reproduction techniques (ART) using gamete donation, the research concluded that the right to be forgotten is a balancing act, which means that it must be articulated with rights that counterbalance it in a given context. Possible claims to a right to erase data add an essential argument favouring non-disclosure of information from gamete donors, despite the international trend to the right of disclosure. If the impact of exercising this right is not widely considered, undesirable absolute anonymity can become the consequence. The right to personal identity, free development of personality, and historicity do not obscure the idea that individuals should also have rights over-identification of their data, including the right to have that data erased in some cases. However, there are no absolute rights in this matter because a necessary balance must be found between them. Therefore, the possibility of this right being invoked by gamete donors facing registering their data will have to consider pseudonymisation. We found that the right to oblivion may endanger what States have progressively fought to safeguard in this growing trend towards donor identification. It is, then, necessary to determine whether absolute anonymity is ethically and legally permissible because what is to be avoided with the prospective and retroactive interpretation of the rights of the child may be rendered impossible if there is not the necessary ethical consideration of the effects of this right on such an important issue. Absolute anonymity seems to us to be ethically and legally undesirable since fundamental rights are at stake. In the balance of fundamental rights, the right to delete should only mitigate the donor's right to privacy with ponderous reasons that justify the removal of anonymity. However, having the right to know genetic heritage is not the same as having the right to learn the gamete donor's name and contact him/her.

Regarding Public Health, combined arguments framed on consequentialist and non-consequentialist ethical theories and human rights led us to conclude that there seems to be no basis for the exercise of the right to be forgotten regarding health data when there are imperative public health motives.

Proportionality is the critical factor concerning colliding human rights. Nevertheless, the research concluded that the burden of proof is on the health care authorities' side to show compelling reasons, and therefore a moral duty, to preserve (and eventually share) patients' health data. However, data controllers should destroy personal data as soon as compliance with public health interest is over. Otherwise, the sacrifice regarding privacy is not proportional.

The thesis's overall conclusion is that the current problems of health data protection and, in particular, the admissibility of the right to have these data deleted poses a new dilemma. A response could be found by breaking new ground, in which biolaw can provide an autonomous branch to provide a framework to meet the challenges of modern societies in terms of privacy and health data protection. The emancipation of biolaw finds echoes in recognition of part of the legal doctrine that understanding this matter's complexity requires an articulation with other branches of knowledge, particularly bioethics. Besides, it is difficult to balance individual and public interests; hence, proportionality should be a critical factor. Here, as in other areas, it is the possibility of choice that defines autonomy and self-determination. However, the law's provisions require a distinction between a technical possibility and what is humanly desirable to protect privacy.

Keywords: autonomy; bioethics; biolaw; COVID-19, data protection; gamete donation; gender transition; health and genetic data; human dignity; identity; privacy; public health, right to be forgotten.

23 Defensive Medicine and Caesarean Section in Brasil

Edson Luciano Rudey

Introduction: When based on medically indicated, cesarean sections can prevent maternal and neonatal mortality. However, as any other surgery, they are associated with risks to the health of both women and fetuses. Despite the known risks of cesarean sections, their global rate has increased in recent decades. Brazil has a high cesarean rate that cannot solely be explained by the clinical conditions of women. The World Health Organization (WHO) advocates for the reduction of cesarean rates and recommends using the Robson Classification as a tool to study, monitor, and compare these rates to help reduce the number of cesarean sections. There are several causes for the increase in cesarean rates, as no clinical justification can account for the totality of this increase" is a more concise alternative. Thus, cesarean sections have been performed without medical indication as well. They are also motivated both by respect for autonomy through cesarean sections requested by mothers and reasons such as economic, social, cultural motivations and defensive medicine, which has been increasing due to doctors' fear of litigation. The WHO recommends that cesarean sections be preferably performed when necessary and states that efforts should be made to reduce these rates.

Objectives: To report and analyze cesarean rates in Brazil according to the Robson Classification, and determine if Brazilian obstetricians perform cesarean sections as a form of defensive medicine (defensive cesarean).

Methods: Data were collected from the Brazilian Live Birth Information System (*Sistema de Informações sobre Nascidos Vivos*) that contains data of the entire obstetric population, 11,774,665 live births from 2014 to 2017, according to the Robson Classification groups of the Information System on Live Births (SINASC). Additionally, a cross-sectional descriptive survey was conducted with 403 gynecologists and obstetricians in Brazil, using a questionnaire on litigation and defensive medicine in obstetrics.

Results and Discussion: Despite the recommendation by the WHO that cesarean sections only be performed when necessary, the autonomy for cesarean sections at maternal request should be respected. However, there is no justification based on other bioethical principles for doctors to routinely offer cesarean section as an alternative to normal delivery without clinical justification. Therefore, obstetricians should

follow the professional responsibility model in medical ethics, which is based on the principles of autonomy and beneficence of pregnant women, as well as beneficence obligations toward the fetus. Questions remain regarding whether pregnant women always their autonomy have respected in Brazil, especially when they wish for a normal birth, as data suggest that women do not receive the necessary support in these cases. Thus, the informed consent process regarding the delivery mode should be transparent, without letting professional interests influence this decision, since cesarean sections are being performed unnecessarily and without the mother's request. Several studies have already supported this statement, using defensive cesarean sections for instance. The cesarean rate in Brazil is high (55.8%) even among Robson groups 1 and 2, which consist of nulliparous women with favorable characteristics for vaginal delivery. The cesarean sections performed in these two groups create a cycle that increases the Robson Group 5, which accounts for the largest overall cesarean contribution in the country. Although vaginal delivery after a cesarean section is safe, it is an unsupported procedure in practice. Results on defensive medicine demonstrated that 94.5% of participants perceive obstetrics as carrying a higher risk of litigation, while 80.6% of participants have been sued or know an obstetrician who has been sued. Obstetricians reported practicing defensive medicine by performing cesarean sections to avoid litigation related to vaginal delivery. Obstetricians who were sued, knew a colleague who was sued, or perceived that obstetrics had a higher risk of litigation were statistically significantly more likely to perform defensive cesarean sections.

Conclusion: The increase in undergoing cesarean sections for women in Robson groups 1 and 2 leads to an increase for Robson group 5, creating a cycle that increases cesarean rates in Brazil. This indicated that the performance of cesarean sections on nulliparous women should, whenever possible, be avoided to decrease their rates. In addition, it is necessary to consider defensive medicine in public policies to confront cesarean rates in Brazil, since obstetricians perform defensive cesarean sections, which is another cause of the increase in unnecessary cesarean rates nationwide. Finally, defensive cesarean sections not only increase rates, but also violate bioethical principles by subjecting women to unnecessary surgery without their consent.

Keywords: Bioethics; autonomy, beneficence, non-maleficence, justice; cesarean section; normal delivery; defensive medicine; Robson classification groups; cesarean rates; Brazil.

24 Evaluation of the Stigma of Psychiatric Physicians in Relation to Psychiatric Disorders and Their Association with Socio-Demographic and Psychological Variables

Antônio Geraldo da Silva

Stigma is a dynamic collective phenomenon that arises when an individual characteristic is inconsistent with the social stereotype created for a given individual. The negative stereotype that the person with psychiatric illness receives can lead to harmful consequences, such as discrimination, decreased demand for professional help, delayed diagnosis, impaired treatment adherence, decreased self-esteem, increased social isolation, and increased suicide rates. Studies evaluating health professionals' stigma are scarce, mainly because it is assumed that this population already has sufficient knowledge regarding mental health. Thus, this work aims to examine the stigma of a specific population, psychiatrists, concerning different mental disorders. Identifying stigma-associated factors by these professionals can support the development and promotion of public policies for anti-stigma and patient support strategies. Also, we investigated the impact of self-stigma on the quality of life of a population diagnosed with Parkinson's Disease, whose prevalence of depression is significant, which increases the risk of these people internalizing a stigma suffered by both neurodegenerative and psychiatric illnesses.

Keywords: Parkinson's disease; psychiatrists; psychiatric diseases; stigma.

25 Biopsychosocial Medical Evaluation of Handicapped People According to a Modern Handicap Concept

Rosylane Nascimento das Mercês Rocha

Industrial revolution and the great wars produced generations of mutilated people, left on their own, with no access to resources of education, culture, leisure, and work. According to the *Instituto Brasileiro de Geografia e Estatística* (IBGE) in 2010 census, Brazil presents 45.606.048 Brazilian population, and 23,9% of total inhabitants have some type of physical, hearing, motor and mental or intellectual disabilities. Due to this reality, several institutions have been created and the legislation has evolved pursuing ensure rights to disabled people. Different rules to enjoy several benefits are misinterpreted and they allow people with mild deformities, with no significant compromise in functionality also could receive the benefits from the law, frequently using the place that belongs to disabled people and with severe functionality limitations. The study questions the conceptual misunderstanding of disability, functionality and work capacity, and the possible bioethical conflict regarding the principle of beneficence and justice in evaluating of declared disability. Thereunto, it aimed to compare the Brazilian legislation and that of other Latin American countries to verify the similarity between the laws and criteria adopted, verifying Brazilian legislation, which is fragmented, suggesting in the end the Consolidation of standards rules along the lines of what happened with labor laws in the country. An analytical study was carried out comparing the use of IF-BrA applied by expert doctors and assistants, from the database provided by the INSS, and the analysis of correlation and significance completed showed there is no difference between the assessment made by the doctor expert and by the social worker, when applied to the rule used to qualify for the retirement situation, according to the degree of presented disability. It also presents three empirical cases of assessment of the person with disabilities related to the assessment by applying the basic sets of the International Classification, for the purpose of granting benefits available in specific legislation. The results show that the use of basic sets available on the website www.icf-core-sets.org helps in the assessment of people with disabilities, and it can be considered as an important tool for granting benefits to people with disabilities in Brazil. Results still point the possibility of bioethical conflict that might occur intending to "help" the petitioner, not portraying the reality of facts and no attending the legislation. The Expert Physician must follow the Medical Code of Ethics, so the suitable professional to perform the evaluation of clinical social and legal criteria is the Physician, and the combined assessment of the ICD and the ICF is indispensable.

Keywords: Disability, Impairment, Functionality, Bioethics, Justice, Equity.

26 Bioethics and Medicine of Ends or Means in Plastic Surgery

Paulo César Mariani

Research hypothesis: The satisfaction of people who undergo plastic surgery depends on the relationship established between doctor and patient, with bioethics being a fundamental moderating factor that permeates the relationship, and this is a determining factor in the probability of complaints and ethical-professional processes occurring.

Objectives: The main objective is to characterize and discuss, in the State of São Paulo, Brazil, the particularities related to plastic surgery care from the bioethical point of view, relating them to the profile of the physician accused and prosecuted, that being: time since graduation, gender of the physician involved, age distribution, public or private nature of the graduation school, and correlate the role of medicine's bioethics, in end or means, in plastic surgery. The specific objectives were to verify the most violated articles of the Medical Code of Ethics, to verify the infractions of article 1 (first) of the Medical Code of Ethics (medical error), to verify the causes of the complaints and ethical-professional processes, and whether the lack of adequate training, both in graduation and post-graduation, is associated with ethical-professional failures.

Methods: A cross-sectional, retrospective, descriptive and correlational study was conducted in research with quantitative and qualitative design in the universe of 421 ethical-disciplinary processes in the period from 2008 to 2017 in the scope of the Regional Council of Medicine of the State of São Paulo - CREMESP. We quantified those who held the title of Specialist in Plastic Surgery, those who held the title of specialist in other specialties, and those who did not hold any specialist title at the time of the research. There were no exclusion criteria, and not all processes had been concluded by the time data collection ended. Among the 421 physicians sued, 233 had already been submitted to trial in the first instance and their results are included in the research. Descriptive analyses were performed, and correlations found with chi-square calculation, with statistical significance at p-value = or < 0.05. 4.

Results: The study found that most physicians are male, experienced in professional practice, aged over 40 years, trained in private and public schools nationwide, with 47.74% of physicians having a specialist title (TECP). Professional Liability (mal-practice, imprudence, negligence) was the most incident complaint (28.43%), followed by Medical Advertising (24.19%) and Relationship among Physicians (10.39%). The most violated articles were the 18th, 51st, 75th and 01st, respectively. In this period 233 physicians were judged, of these, 133 received punishments; 80 were discharged and 20 were dismissed. Of the 133 physicians punished, 10.5% received penalty A and 35.3% penalty B (confidential), 33.1% received penalty C, 14.3% penalty D and 6.8% penalty E (public). We found that physicians with a specialist title in plastic surgery have more severe penalties, penalty C (Public censure in an official publication), penalty D (Suspension of professional practice up to thirty days) and penalty E (Termination of professional practice), compared to physicians who do not have the TECP. Younger women and older men also receive more severe penalties (penalty C and E respectively). In the complaints of repeat offender physicians, we observe that it occurs more in male physicians, graduated in public schools, with a specialist title (TECP), in the age groups from 30 to 39 years and over 70 years, showing problems at the beginning and end of the medical career. In the 40 to 49 age group, they occur in men without a specialist title in plastic surgery.

Conclusion: It was found that the physician judged to be Guilty is 3 times more likely to incur the errors related to the articles of Professional Responsibility and 2 times more likely to incur the errors in Human Rights. This study showed that all the failures that led physicians to professional-ethical processes were acts that disrespected the basic principles of bioethics. Bioethics has a fundamental role in the formation of human beings, especially in the formation of plastic surgeons, and should, from the beginning of training to the highest degree, be present in school curriculum.

Keywords: Bioethics, medicine of ends, medicine of means, plastic surgery

27 Bioethics Training in Medical Graduation in Portuguese Speaking Countries

Ana Carolina Alvares Lavigne de Lemos Tavares

Introduction: It is known that the curriculum is a fundamental tool for educators and that the teaching of bioethics is fundamental for good medical practice. Studies report that there is no consensus on the teaching of Bioethics in undergraduate medical education, and a key issue is that there are still no minimum curricular parameters. The literature points to the diversity existing in the curricula of undergraduate medical courses in relation to the teaching of bioethics, reinforcing the need to systematize and deepen studies in this area, with the aim of qualifying the training of our future professionals.

Objectives: General: establish criteria to compose a nuclear curriculum in bioethics in Portuguese-Speaking countries. **Specific:** establish the differences between the Bioethics curricula in Portuguese-speaking medical schools and define the key criteria for composing the nuclear bioethics curriculum.

Methods: As a first step of the research, an integrative review was carried out with the objective of understanding the methods used in the teaching of bioethics in undergraduate medical education around the world. The databases used were Pubmed, Scopus and Web of Science. The keywords used based on their appearance in the title and abstract were "bioethics" and "medical ethics". In total 2993 articles were identified and 72 met the preselected criteria and were included in the review. The second stage of the research consisted of a cross-sectional, descriptive study to analyze the bioethics curricula of the faculties of medicine in the Portuguese-speaking countries: Angola, Brazil, Cape Verde, Portugal, and Mozambique, and to compare the contents of the curricula with the UNESCO Bioethics Core Curriculum. The curriculum analysis included a summary approach based on qualitative content analysis and a quantitative approach using descriptive statistics and absolute and relative frequencies, data were organized and analyzed in Microsoft Excel 2016.

Results: Most of the studies in the integrative review led to the understanding that there is still no consensus on the ideal method for teaching ethics, suggesting that this may affect the feeling of unpreparedness felt by medical students when facing ethical issues in clinical practice, despite the theoretical background acquired. In the cross-sectional study developed, 51 medical schools from Brazil, 07 from Portugal, 02 from Angola, 01 from Cape Verde and 01 from Mozambique were analyzed. It was observed in the analyzed medical schools that only 64.5% of these schools had a minimum workload of 30 hours, recommended by UNESCO's bioethics core curriculum, and a variation regarding the existence of the discipline in the pre-clinical and clinical years of the medical course in the great majority of the analyzed schools. The present research also showed that the contents of the curricula analyzed in several countries of the Portuguese-speaking world were not explicit, and it was only possible to analyze the contents in the faculties of Portugal and Brazil. In this analysis, it is verified that the curricula in Brazil mostly worked themes related to the society, such as human dignity and human rights, social responsibility, and health, followed by equality, justice, and equity. In Portugal, the curricula focus more on topics related to individual responsibility for medical action, such as individual autonomy and responsibility and respect for human vulnerability and personal integrity. Thus, there is a need for a nuclear curriculum to standardize the teaching of bioethics in medicine in Portuguese-Speaking countries (and other countries). Based on these results a proposal for a nuclear bioethics curriculum addressing the current relevant bioethical issues in modern societies based on the UNESCO Bioethics Core Curriculum was developed, preferably as a compulsory subject with a longitudinal program offered each year of medical school with a standardized curriculum, but with enough flexibility to adapt to the specificity of each cultural context.

Conclusion: As conclusions, we could highlight the diversity of curricular organization regarding the theme of bioethics and the lack of formalization of the subject in these curricula. Given the valuable resource that the teaching of bioethics brings to clinical practice, we propose that medical schools in Portuguese-Speaking countries update their curricula, encompassing minimum criteria, and that these be similar, based on common sources and with the cultural specificities of each continent.

Keywords: Bioethics, curriculum, medical education, Lusophony, Portuguese-Speaking countries

28 Advance Care Planning in Oncology: Challenges in Clinical Practice

Laiane Moraes Dias

Advance care planning is a process of discussion by which patients with serious illnesses are empowered to articulate their personal preferences and goals to make decisions regarding current and/or future care. It is an important domain in providing high-quality palliative care. Therefore, physicians must have skills to adequately discuss the prognosis, the uncertainty of treatment outcomes and provide recommendations for end-of-life care options, when it is appropriate for each individual and his or her disease course. Though widely recognized as an integral component of oncologic care, advance care planning has not been systematically implemented into clinical practice.

Given the scarce literature on advance care planning and on its difficulties in oncology practice in Brazil, this thesis aims to explore physicians' barriers in performing advance care planning in patients with cancer, thus enabling as a final goal to propose a guide for discussion of advance care planning for Brazilian physicians.

A literature review about advance care planning and a systematic review of the literature about therapeutic refusal by elderly patients with cancer was carried out, as a preamble for the main objective of this study, to better investigate the autonomy of elderly cancer patients and to identify the reasons related to therapeutic refusal, since it is a topic frequently discussed in advance care planning and is still a challenge in daily practice. Two empirical studies were performed, using the *"Decide-Oncology"* questionnaire, an instrument used to identify the perception of physicians' barriers about goals of care discussion and advanced care planning. In one study, the adaptation to Portuguese and validation of the content of the "Decide Oncology" questionnaire was carried out, and a pilot study with resident physicians to explore the barriers to addressing advance care planning was performed. In the second study, the "Decide-Oncology" was administered, and a quantitative and qualitative methodology was used to explore Brazilian oncologists' perceived barriers to discussing goals of care and advance care planning.

For most clinicians, advance care planning and goals of care discussions are challenging and often avoided due to a variety of factors, namely lack of training, insufficient time to have a conversation, patients', and families' difficulty in accepting a poor prognosis, uncertainty about prognosis, and lack of palliative care teams, that were important barriers perceived by physicians to initiate and conduct advance care planning discussion in the two empirical studies. A positive

impact on the willingness to participate on goals of care discussion was associated with previous training in this topic. Finally, considering the need for practical guides for advance care planning adapted to the Brazilian reality, based on empathic communication strategies, a guide with recommendations of current evidence, which contains information about when and how to do it - the step by step from preparation, exploration of patient's values and perception about disease, to the advance care planning registration, including advance directives records- and instruments already validated to Portuguese language (Brazil), to encourage its elaboration and then, facilitate the practice.

Exploring physicians' barriers to performing advance care planning could help prioritize the next steps for future studies aimed at improving this issue, helping clinicians better support patients and families through shared decision making based on patient values and self-identified goals.

Keywords: Advance care planning, autonomy, communication, end-of-life care, oncology, shared decision-making

29 Diagnosis of Neuromuscular Diseases in Inbred Communities: Obstacles to Implementing the Principle of Autonomy

Isabella Araujo Mota Fernandes

Introduction: The Brazilian northeast is historically marked by the high prevalence of consanguineous, with a consequent increase in the frequency of auto-recessive neurodegenerative genetic diseases, with heterogeneous phenotypic and genotypic presentation. The communication of these diagnoses must be centered on the patient, the doctor and legal guardian triad, to respect the autonomy of those involved. In this way, this research aims to understand the practical challenges of respecting the autonomy of patients with rare diseases during the communication of diagnosis of spinal muscular atrophy (SMA), a neuromuscular disease, comparing the dissemination of the diagnosis in endogamous versus non endogamous regions and prepares a communication guide.

Method: This is a cross-sectional, quantitative, and qualitative study, conducted through a structured questionnaire and semi-structured interview answered by patients diagnosed with SMA or their families. The sample was randomly selected from the patient registry in non-governmental associations. The invitation to participate began after approval by the ethics and research committee of HULW, Federal University of Paraíba and signing of the free and informed consent form. Additionally, a systematic review was carried out on the Pubmed, Bireme and Scopus portals with the following descriptors: ((Muscular Disorders) OR (Neuromuscular Disease)) AND ((Bad news communication) to develop a communication guide for the diagnosis of neuromuscular diseases.

Results: The sample consisted of 100 volunteers, 83% female, aged 36.65 (±10.19) years living in all regions of Brazil. The inbred region, represented by the Northeast region, although less economically favoured, presented greater satisfaction and inclusion in medical care and health services, with fewer psychological traumas and signs of posttraumatic stress disorder related to the time of diagnosis of SMA. However, non-inbred regions reported the presence of strong waves of emotion related to the communication of the diagnosis of SMA, in addition to sleep problems, feelings of irritability, bravery and the presence of bad thoughts. Among the 50 family caregivers interviewed, those who had the responsibility to report the diagnosis of SMA to their children reported psychological trauma and post-traumatic stress syndrome regardless of the region in which they lived. Fifty-seven volunteers participated in the semi-structured interview with reports of positive and negative experiences related to diagnostic clarification, communication of prognosis, affective memory related to the communication process and advice to physicians. The elaboration of the EMPATIA guide suggests seven steps for effective communication: empathy, message, prognosis, welcoming, time, individualization, and autonomy.

Conclusion: The individualized transmission, clear, honest, and welcoming, emphasizing the positive aspects, in the presence of family members and with the possibility of continuous follow-up is important to meet the demands of communication. Among the barriers found, we highlight the lack of empathy, the estimation of lifetime and the absence of guidance and follow-up. The degree of satisfaction with the care provided and the feeling of inclusion in health services were essential to reduce the presence of signs of post-traumatic stress syndrome in the inbred region. Respecting and individualizing the medical trinomial/patient/legal guardian during the communication of the diagnosis of SMA to children and adolescents reduces the frequency of psychological trauma and post-traumatic stress syndrome in family members. Thus, communication planning since the clarification of the diagnosis, prognosis, and evolutionary follow-up, understanding the feelings of the interlocutors, optimizes time, strengthens the doctor-patient relationship, reduces the stress of the attending physician, and individualizes each context, respecting the autonomy of those involved.

Keywords: Communication, consanguinity, doctor-patient relationship, inbreeding, neuromuscular diseases, spinal muscular atrophy.

30 The Personal Expression of Medical Doctors Regarding Bioethics, Quality of Life at Work, and Patient-Physician Relationship

Mário Afonso Filho e Maluf

Background: This scientific work dealt with issues that concern the Brazilian medical class and focused on the themes of Bioethics, Quality of Life at Work (QVT), and the doctor-patient relationship. The first survey at the national level was carried out with registered doctors and their valid e-mails that are part of the database of the Department of Informatics of the Federal Council of Medicine (CFM). A structured questionnaire was used as a research tool, in which eight specific questions were asked that dealt with some factors that are part of the work context of the Brazilian medical class, and it was also proposed to know their feelings and understanding of bioethics in this relationship. The second survey was carried out through a survey on the websites of national and regional representative medical entities in Brazil, seeking to identify a negative aggravating factor of QWL in the pandemic period, which was an increased risk to the lives of these workers who did not properly obtain the equipment for personal protection (PPE). This fact may compromise the second level of the Maslow scale in your work environment during the Covid-19 pandemic. At the end of the work, we observed that an inadequate QWL can affect, in the personal field, their feeling and understanding of bioethics, an essential basis for good medical practice, since we cannot fully dissociate the personal figure of the man and this professional being.

Methods: The opinion survey consisted of a structured questionnaire composed of eight questions relevant to the medical work context sent by the Department of Informatics of the Federal Council of Medicine (DICFM) to a target population of 360,841 physicians, 95,022 of which had valid email addresses, with a return of 426 questionnaires. This result was 57.75% higher considering the Homogeneous Sample, which requires a return of 246 questionnaires for validation, since it is a homogeneous population of doctors, or also considering a Heterogeneous Sample, with the result of 11% higher for a non-specific population that minimally needs the return of 384 questionnaires for validation. Both results, regardless of the type of survey sample, were validated by the amount returned by the questionnaires sent. Both results, regardless of the type of survey sample, were validated by the amount returned by the questionnaires sent. In the second work, also national in scope, collaborative of the first, the topic of not properly distributing PPE to physicians during the Covid-19 pandemic was chosen, enrolling all national and regional medical entities that had until that moment active websites. Since the data from the complaints were made by the doctors themselves individually, and from specific news on the subject that occurred in the researched period, between 01-01-2020 and 08-31-2020. Both surveys had negative situations relevant to QLW. All data from the first and second surveys were later tabulated in Excel spreadsheets, analyzed and completed.

Results: The positive results obtained in the first survey were observed through the free and personal expression of the Brazilian medical profession; expressed individually and autonomously; with an approximate positive average of 55% of the sum of the questions formulated in the structured questionnaire. This result obtained was derived from the sum of the positive responses for the items identified as: "Totally agree" and "Agree". These expressions in which feelings and understanding about the individual perception of bioethics are identified where it can be deconstructed from this context researched and related to QWL. In the second study, it was evident that the non-distribution of PPE was verified by a massive result of more than 3,000 individual complaints by doctors, and also 73 specific news on the subject on the official websites of entities representing the medical profession, during the period surveyed of the pandemic by Covid-19, between 01-01-2020 and 08-31-2020, which demonstrated the commitment of the second level of the Maslow scale for the Brazilian medical class.

Conclusions: The research demonstrated with its clearly positive results that depending on the QWL it can compromise; resulting in more than 50%; the feeling and understanding of bioethics in the doctor-patient relationship, one of the pillars for the good practice of medicine. Complementing this result, there was another reinforcement of 3,000 complaints about the non-distribution of PPE, which had an even stronger meaning for the development of medical stress due to the increased risk to these professionals' lives, therefore compromising their QWL. The most important result that we can extract from this scientific work is to build a new look at the medical profession so that it can have QWL in the provision of its services. Therefore, attitudes must be aimed at prevention and recovery in the field of worker health and biolaw. This research must be seen as a service for the improvement of Brazilian public health since almost 90% (89.3%) of the medical staff are linked to this sector, whether at the municipal, state, or federal level. These alarming results should be further explored and contextualized in new studies since the result can at least demonstrate

a feeling, a thought about this deteriorated relationship. Objectivity, concreteness, and whether or not there was an "action" in the effective commitment in the doctor-patient relationship through the execution of any Medical Act (ML) was not researched and is not the subject of this research (Lei do Ato Médico, 2013) touched by a possible act of negligence and/or medical recklessness. The studies carried out should also be proposed in other countries, with a focus on the management of medical human resources (HR), contemplating a public health vision. Finally, the physicians were able to freely, personally, and spontaneously express their thinking, their feelings, and their understanding of this bioethics and QWL relationship, which were expressed through this opinion survey.

Keywords: Bioethics, burnout syndrome, Covid-19, health services management, internal marketing, quality of life at work, misthanasia, personal protective equipment, public health.

31 The Bioethical Principle of Beneficence Applied to the Surgical Treatment of Severe Obesity

Ivan Gregório Ivankovics

Background: Over the last years, obesity has become a public health problem, both by the growing number of individuals affected and by the comorbidities related to this disorder. The evaluation of the quality of life has become fundamental for making the decision about types of treatment.

Objectives: analyze the quality of life in two groups of patients: those with obesity in class II and III, candidates for bariatric surgery, and patients already submitted to surgical treatment of obesity.

Method: The WHOQOL-Bref questionnaire was used. The general characteristics of the preoperative group were a mean age of 38.68±9.43 years; 85 women and 19 men; a mean weight of 126.64± 23.01 kg, and a mean BMI of 47.41±7.98 kg/m². The general characteristics of the postoperative group were a mean age of 40.33±9.38 years; 46 women and 9 men; a mean weight of 72.14±14.53 kg, and a mean BMI of 27.53±4.05kg/m².

Results: The results showed that in the preoperative group, the perception of quality of life, health satisfaction (HS/Q2), and the physical domain (PhyD) require improvement, whereas the psychological domain (PsD), social relationships (SR), and the environment are regular. In the postoperative group, Q1, Q2, PhyD, PsD, and SR are classified as good, and the environment is classified as regular. When compared to the means and scores, there is a statistically significant difference between the groups in all variables studied. In all criteria considered, there was an improvement in the quality-of-life conditions of the population studied.

Conclusion: Therefore, the improvements generated by bariatric surgery on the health conditions of the population allowed for improvements in the quality of life of the patients. It follows that from an ethical perspective, in accordance with the bioethical principle of beneficence bariatric surgery should be recommended by the surgeon and the healthcare system should have this modality of treatment in its basic healthcare package.

Keywords: Bariatric surgery, obesity, obesity surgery, quality of life.

32 Hepatitis B Virus Infection in Children and Adolescents in the Brazilian Amazon: Epidemiological and Bioethical Aspects

Alessandre Gomes de Lima

Background: Hepatitis B Virus (HBV) infection is an important public health problem, affecting approximately 2 billion individuals. The World Health Organization (WHO) recognizes the Amazon as a highly endemic HBV infection, and the state of Acre has one of the highest Brazilian rates of this infection. Children and adolescents represent a high-risk group for chronic HBV infection. Bioethics has the function of ensuring the well-being of people, guaranteeing and avoiding possible damages that may occur to their interests, and providing the professional and those who are served by him, the right to respect and will, respecting their beliefs and values. The present study aims to investigate the epidemiological aspects of hepatitis B in children and adolescents, discussing the results found in light of bioethical principles.

Material and Methods: This is a cross-sectional, retrospective study, based on a time series of cases, whose notification data were extracted from the Notifiable Diseases Information System (NDIS). Regarding the bioethical discussion, a bibliographic review was carried out, including the articles searched on the Scientific Electronic Library Online (SCIELO), Latin American and Caribbean Literature on Health Sciences (LILACS) and the National Library of Medicine (PUBMED), using the following descriptors: hepatitis B, vaccines, bioethics, and humans.

Results: 889 cases of hepatitis B were reported in the study population, evidencing a predominance in the age group from 15 to 19 years old (68%), female gender (62%), self-declared brown color (72%), living in the urban area (55%), incomplete primary education (31%), probable sexual source (51%) and chronic clinical form (56%), and most individuals had no vaccination schedule against this infection (34%). Although the autonomy of adolescents in relation to their choices is recognized, they constitute a group that deserves special attention, after all, adolescents can use this principle in an erroneous way, exposing themselves to risk situations, which make them susceptible to diseases, besides that, some decisions depend on the consensus of the person in charge, which can interfere with the adherence to vaccination against HBV.

Conclusions: The epidemiological characteristics of HBV infection corroborate the importance of prevention by immunization, emphasizing that the complete vaccination schedule increases the effectiveness of immune protection. In this sense, the adolescent's right to progressive autonomy is recognized, regarding the choice of immunizations against hepatitis B, however, it should be considered that these individuals are instructed on the individual and/or collective benefits of vaccination, covered by activities of health education by qualified professionals, aiming to expand global immunization coverage, in addition, the conduction of treatment and prevention of HBV should be widely discussed in association with bioethical principles, developing health actions which can guarantee to the individual, the principles of autonomy, beneficence, non-maleficence, and justice.

Keywords: Bioethics, hepatitis B, infection.

33 Walking the Experience of Dying: A Phenomenological Study with Oncological Patients at the End of Life

Eduardo Manuel Neves Oliveira Carqueja

Background: This study has the main goal of comprehending the adaptation process to the process of dying in palliative care patients, exploring, the emerging potentialities and vulnerabilities experienced by a patient at the end of life, the perception of autonomy and dependence during this stage, how the social support is valued in the process of dying, what are the coping strategies used by a person throughout the process of dying, in a bioethical perspective, what implications result from the loss of autonomy and increase in dependency and, at last, also in a bioethical perspective, what are the narratives used by a person at the end of life and its implications for the present juridical regime of the advanced directives for living will.

Material and Methods: To pursue these goals, a longitudinal approach was selected as the most appropriate format to study patients with an advanced oncologic illness in a palliative care unit, at three moments of data collection, i.e. through three semi-structured interviews to each participant. The first interview (T1) was conducted during the first psychological palliative care appointment involving 21 participants, the second interview (T2) took place whenever an aggravation in the participants' clinical condition occurred involving 8 participants fulfilling the 1st and 2nd interview, and a third interview (T3) being carried out in the closest moment possible to death, involving 7 participants that went through the 3 interviews. Qualitative analysis of data proceeded according to the principles of *grounded theory* using the program *Software Nvivo 10*.

Results: Data analysis indicates that the patient's perception of their illness throughout the process of dying, has an evolving character of emotional, cognitive, and behavioural adaptation, filled by positive and negative perceptions, where *"what I feel"*, *"what I think"* and *"what I do"* is altered to *"what I feel"*, *"what I think"* and *"what I don't do"*, that seems to be derived from the dependency resulting from lack of strength or other physical symptoms. The dependency, not being the only dimension contributing to this perception of dying, has considerable weight in the adaptive process of patients at the end of life.

Conclusions: This perception is influenced and influences the perception of autonomy and vulnerability and is affected by informal social support, behavioural reactions, coping strategies, and internal and external resources. Patients feel more or less autonomous according to their physical condition and not by their cognitive and/or decision-making ability and most of them have no knowledge of the advanced directives for living will.

Keywords: Death, Dying End of Life, Phenomenology

34 Equity in the Access of Chinese Immigrants to Healthcare Services in Portugal

Sandra Lopes Aparício

Background: International studies indicate that Chinese immigrants face barriers when trying to access healthcare in the host country. The aim of this study was to identify the barriers that Chinese immigrants face when accessing the Portuguese National Health Service.

Material and Methods: An observational, cross-sectional, and quantitative study was carried out via a bilingual Portuguese/ Mandarin self-completed paper questionnaire was applied. The study population consisted of individuals with Chinese nationality who were residing in mainland Portugal for at least one year and aged 18 years or over. A total of 304 individuals answered the questionnaire.

Results: The results show that 284 (93.4%) of the participants had already sought healthcare in Portugal. The participants identified language difficulties and health professionals' lack of knowledge of Chinese cultural habits as the most significant barriers to accessing healthcare in Portugal. Of a total of 165 participants who sought healthcare in China, confidence in treatment outcomes and health professionals' knowledge of Chinese cultural habits were the reasons given by 151 (91.5%) individuals.

Conclusions: This study reveals the existence of linguistic and cultural barriers that can condition the access of the Chinese immigrant population to healthcare systems. Immigrants' access to healthcare can be promoted via policies that contribute to proficiency in the Portuguese language and medical literacy among the Chinese immigrant population. It can also be promoted by raising the awareness of health professionals about Chinese cultural habits.

Keywords: Healthcare access, Chinese, Barriers, Equity, Traditional Chinese Medicine

35 Consent in Biobanks for Biomedical Research Purposes

Cíntia Águas Pereira

Background: Biobanks, being defined as organisations/legal entities that manage human biological materials, associated with relevant information, have evolved over the last few decades to become large-scale research infrastructures with a transnational aptitude for biomedical research purposes. Ideally endowed with highly specialised human resources, their activity is supported by increasingly powerful, fast, and low-cost analytical equipment and technologies. Biobanks can either be state-owned or operate in hospitals or universities, spanning the public, private, or social sectors, and be pathology-oriented or representative of a given population, or segment of the population. In any case, these versatile organisations are part of an "ecosystem" involving patients and patient organisations, health professionals, researchers, and other experts, but also funders and political and regulatory bodies, yet always interacting with civil society. Despite the growing establishment and professionalisation of these structures in other countries, in Portugal, many aspects of the constitution and activity of biobanks, as well as their relationship with donors of samples and sensitive data, remain to be determined. Ownership of samples and their secondary use, patents and commercial gains, communication of results and sharing of benefits, the processing of personal data, or the protection of privacy are key concerns regarding the activity and regulation of biobanks in urgent need to be addressed and updated in the Portuguese context. Scattered regulation, in need of revision and unification in order to face new realities, in which the scope of consent is not always clear, creates uncertainty and runs the risk of not fully respecting personal dignity, integrity, and human and fundamental rights. On the other hand, it may hinder competitiveness and the effective participation of Portuguese biobanks in international research projects. This doctoral dissertation aims to conceptualise biobanks and analyse their value in the context of biomedical research, by analysing their historical trajectory and the ethical and procedural assumptions of autonomy, consent, and governance. The ethical values stated, from which derives the requirement for consent, are brought to the fore by biobanks in the collection, processing, storage, access, analysis, custody, and distribution of biological samples of human origin, with a view to contributing to national policies and internal procedures that are coherent and favour innovative and socially responsible scientific research.

Material and Methods: To this end, a theoretical, descriptive and reflective approach the ethical basis of autonomy was established vis-a-vis with the relation of the person with the body and the biological sample used by science. The different types of biobanks operating in the international space were then conceptualised in terms of common elements and distinctive features, based on existing realities and an analysis of comparative law, including international norms and conventions, as well as self-regulation. A categorisation or "taxonomy" of biobanks was also carried out, illustrated by case studies and jurisprudence, selected for their durable impact on legislative evolution, procedures and current activity of biobanks. In a second part, a historical and contextual overview of the role of consent in research with human beings was made, with critical questioning of the constitutive elements of autonomy and consent, highlighting its practical implications for research. In the specific approach to possible models of informed consent, it was discussed that the traditional model of informed consent can hardly be transposed to the specific context of biobanks for biomedical research purposes.

Results and Conclusions: As a first conclusion, the debate on the exercise of autonomy, in its premises and limits, as well as consent as a form of legitimation for the use of human biological samples for research purposes, should be read in the light of the symbiotic relationship that biobanks maintain with the scientific community, participants and society. Consent remains one of the most debated ethical aspects in this context. Indeed, clinical and genetic data are among the most sensitive personal information, as it establishes a route of the current and future health of an individual and of those who are genetically related to him/her which, if exposed, may jeopardise fundamental rights, with the risk of discrimination and stigmatisation of those involved and even of specific groups or populations. New models of consent (broad, dynamic, conditional, to name a few) add new opportunities and challenges and mark a departure from classical acts of consent. Not to be confused with the regulation of data protection, consent should maintain its ethical matrix as it evolves to encompass the typology, purposes and activity of modern biobanks for research, while considering the sample and data donors and genetic families, as well as cultural matrixes and communities. The thesis proposal pursues the desirable balance between the protection of the person who is the "source" of the samples and the need for research which is vital for humanity, assuming, from a conceptualization of autonomy of which informed consent is a corollary, that the Primacy of the Human Being is not incompatible with an ethical calling to contribute to biomedical research for the common good, in a spirit of solidarity. Nor can Ethics

and Law dissociate themselves from the relevant advances in Medicine and Science, from whose fruits all should be able to benefit equitably. We advocate, therefore, that the creation of structure and the elaboration of policies and procedures for the activity of biobanks for biomedical research should include ethics "by design and by default". This should be done when evaluating, reflecting and proposing recommendations and norms directed to professionals (technical, ethical, quality and biosafety standards); to donors (information, consent, policies for processing and access to data and samples, non-discrimination, return of actionable results); to researchers (policies for registration, access and follow-up of samples and data) and to funders (commercialisation issues, industrial property, return on investments made), taking into account the ethical, legal and social implications thereof (ELSI). From this reflection, a proposal of principles and fundamental axes of action was elaborated to support the development of policies and models of consent articulated with the constitution, organisation and sustainable governance of biobanks, that are harmonised with the best international practices and applicable to the Portuguese reality, at the following levels: a) ROP Level - Legal-Ethical (Required Operational Practices) - Analysis and elaboration of principles, operational concepts, standards and best practices. b) POL Level - Ethics-Governance (Policy) - Definition of the biobank management policy, in line with the ROP. c) SOP Level - Standard Operating Procedures - Planning, application, revision and approval of the processes and those responsible for them. d) GAP Level - Ethical-Procedural (Guide for Actions and Processes). In conclusion, good governance of biobanks is based on proper policies and strategies, taking into account their mission and purposes, with a view to: a) Optimise the use of samples and associated data, in terms of their quality, quantity/volume and organisation; b) Allow fair and judicious access to samples and data for projects of ethical and scientific merit; c) Facilitate cooperation between institutions, through a robust and harmonised framework and practices; d) While respecting the inherent dignity, integrity and autonomy of individuals and safeguarding the privacy and other fundamental rights of sample donors (participants); e) Foster public trust by continuously involving participants and citizens; f) Contribute to the advancement of medicine, to the health and well-being of all people, and ultimately to the common good.

Keywords: Biobanks, autonomy, biolaw, biomedical research, informed consent

36 Scientific Development in the Northern Brazil Region An Analysis of the Contribution of Research Ethics Committees

Aparício Carvalho de Moraes

Context: The thesis proposes a qualitative and quantitative study on the contributions of Research Ethics Committees in the Northern Region of Brazil to regional scientific development.

Objectives: Analyze this contribution in three dimensions: (1) its history, aiming to evaluate the contribution of the Committees to the development of science in the Northern Region, (2) the spatial distribution of the Committees, and (3) identify the production, areas of knowledge, and research projects that go through the committees.

Method: The research consisted of data collection from websites, especially the National Research Commission (CONEP) and Plataformabrasil, a database of all projects involving human subjects. Thus, it will consist of documentary research with data collected from primary sources, a literature review, and interviews with members of the Research Ethics Committees. Bioethics will be considered an interdisciplinary concept that substantially contributes to the understanding of research involving human subjects. The guiding question will be: What is the contribution of the Research Ethics Committees in the Northern Region to the development of Science in the Region? The hypothesis of this research is that there is a correlation between the existence of Research Ethics Committees and the main indicators of regional scientific development.

Results: The thesis aims to contribute to the formulation of a research agenda on the development of Science in the Northern Region. In broader theoretical terms, the study also argues that this analysis based on Research Ethics Committees has its legitimacy, and a more accurate knowledge of the development of Science in the Northern Region depends on investigations of its local development. It also aims to analyze the bioethical implications resulting from the activities of the Committees, such as the protection of traditional populations' knowledge and other migratory flows, as well as the benefits and risks associated with research.

Keywords: Amazonia, bioethics, Research Ethics Committee

37 Rare Diseases and the Provision of Drugs by the State. A Bioethical Debate on the Importance of Human Life, the Judicialization of Life and the Achievements of Patients with Rare and Ultra-Rare Diseases in Brazil

Mariana Fonseca Ribeiro Carvalho de Moraes

The anti-Covid19 vaccination campaign has been fortified on the positive effects that immunization is bringing the nations, since infection rates, hospitalizations, and deaths have been falling according to the data in constant disclosure by government officials organs, and the channels of communication. In Brazil, the effective and free National Vaccination Program didn´t prioritize patients with rare diseases, who have extreme comorbidities, and who had to follow the calendar prepared by the government. The problematic question is why these "rare people" weren´t considered priorities.

The understanding of the reasons and the resumption of the debate about the rights of patients with rare diseases justify this study, which sought to be based on regular descriptors issued by official government agencies and by critics of rare disease issues in debates made in scientific articles available on the web. We sought to respond to the following objectives: analyze dispensed care of rare disease carriers in the vaccination campaign anti-Covid-19; identify the procedures implemented by the National Vaccination Plan for the Brazilian population over 18 years of age; describe the panorama of the pandemic disease since its discovery to the mutations already disseminated; and evaluate the effectiveness of the plan implemented from the perspective of "rare person".

Keywords: Covid-19, Rare Disease, Public Policy, Vaccination

The Design of the covers of the Book: Mrs. Gili Carmi