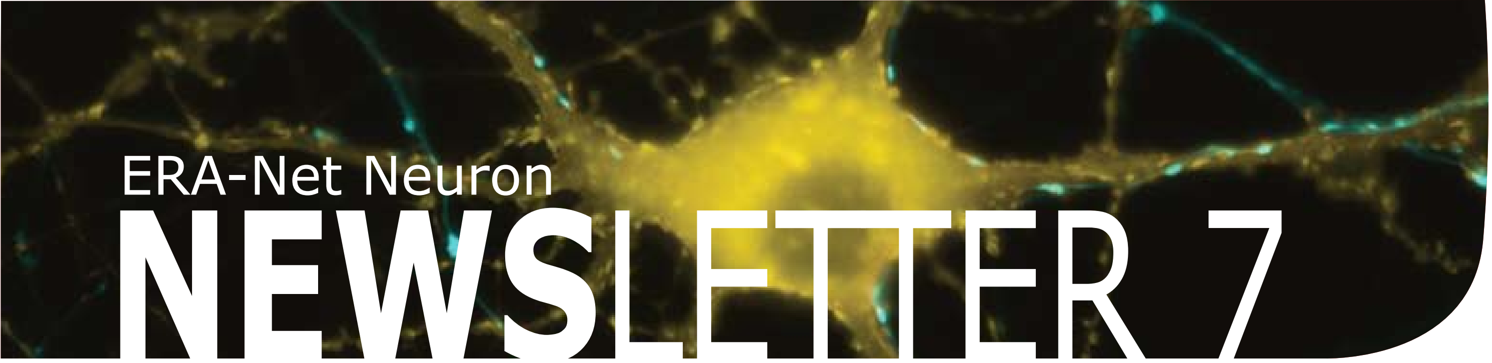

ERA-Net Neuron

NEWSLETTER 7

Neuroethics workshop

The Jerusalem Center for Ethics
October 15th, 2009, Jerusalem, Israel

Canada Sweden Spain Poland Luxemburg Austria France Israel Germany Romania Finland Italy UK

Foreword: Marlies Dorlöchter, ERA-Net NEURON coordinator

The science of neural structure and function is a fascinating area and currently one of the biggest challenges for researchers. Enormous progress has been achieved in the past years in the understanding of human brain function, mainly due to the development of sophisticated methods and technologies enabling non-invasive studies of the brain. Understanding the healthy brain may directly lead to solutions for people with brain impairment due to disease or trauma. Yet, with the explosion of knowledge gain neuroscientists find themselves increasingly exposed to moral-ethical questions and criticism about potentially too deterministic views or new technologies and therapies involving mechanical and pharmacological interventions that might alter consciousness, personality or sensation. From this debate, several years ago 'neuroethics' emerged as a new philosophical field that is meanwhile broadly accepted among neuroscientists.

ERA-Net NEURON organized a workshop, in which experts presented their experiences and research about selected topics and questions from the neuroethics field: Eric Racine addressed the important role of the media coverage of neuroscientific findings for the understanding and acceptance of brain research in society. Avraham Steinberg tackled the issue of how stem cell research can be used for therapeutic approaches to neurological disabilities. Renana Eitan reported how Deep Brain Stimulation, a novel treatment for patients with Parkinson's Disease and some psychiatric disorders, affects the patients' personality. Elizabeth Peel described the participants' perspective and view towards being exposed to neuroimaging. Hemona Soreq gave an comprehensive general overview about neuroethics of brain research. Alan Rubinow presented examples of teaching clinical ethics and the students' responses. The workshop was highlighted by a round table discussion about the ethics of end-of-life decisions specifically in patients with neurodegenerative diseases.

Recordings of the lectures in the workshop can be viewed in the following link in flash and windows version: http://video.tau.ac.il/Lectures/General/Neuro_Ethics

German Aerospace Centre, Project Management Agency

Federal Ministry of Education & Research (BMBF), Germany

Austrian Scuence Fund (FWF), Austria

National Authority for Scientific - Ministry of Education, Researc and Youth (ANCS - MECT), Romania

National Centre For Programmes Management, Romania

The National Centre for Research and Development (NCBIR), Poland

Medical Research Council (MRC), UK

Ministry of Health (MOH), Italy

Academy of Finland (AKA), Finland

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National Research Agency (ANR), France

National Center for Scientific Research (CNRS), France

Institute of Health Carlos III (ISCII), Spain

National Institute for Medical Research (INSERM), France

Chief Scientist Office, Ministry of Health(CSO-MOH), Israel

National Research Fund (FNR), Luxemburg

Swedish Research Council (SRC), Sweden

Canadian institutes of Health Research, Canada

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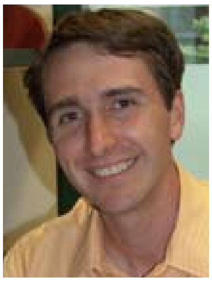
More information can be found in our web page
http://www.neuron-eranet.eu/index.php

Ethics and the public understanding of neuroscience: Perspectives from the media

Eric Racine, Department of Neurology and Neurosurgery & Biomedical Ethics Unit, McGill University, Montreal, Canada



This talk first briefly introduced to the emerging discussion on the ethical aspects of basic and clinical neuroscience, “neuroethics”. The challenge of public understanding of neuroscience and science communication was highlighted as a challenge that informs ethics debates. Second, specific data regarding public understanding of both clinical and basic neuroscience was presented based on case studies to illustrate some of the existing ethics and public understanding challenges. As was reviewed, I have found that: (1) reporting practices for neuroscience research are sub-optimal; (2) a balanced tone (that includes both the potential benefits and risks of neuroscience) is not predominant in media coverage of neuroscience; (3) there several shortcomings in scientific and medical explanations with regards to brain health and portrayal of neuroscience technologies; (4) there is content fostering for public misunderstanding, hype and false expectations (e.g., neurorealism, neuroessentialism); (5) there are multiples sources of ethics debates and controversies and (6) public understanding has been identified by different stakeholders as one of the key socio-ethical issues but little guidance is available to them. Third, I concluded by highlighting the need for further research and practical approaches to tacking problems related to public understanding of neuroscience.

Stem-Cell Research – Scientific, Ethical and Jewish Legal Aspects

Avraham Steinberg, Director, Medical Ethics Unit & Senior Pediatric Neurologist, Shaare Zedek Medical Center, Jerusalem, Israel

The great importance of the discovery of stem-cells lies in their potential to differentiate into all types of cells. Many degenerative disorders can be potentially cured by stimulating stem-cells to differentiate into the appropriate cells that were damaged, introducing them into the degenerative area and hence producing new and healthy cells.

Another possible important use of stem-cells will be in creating entire organs.

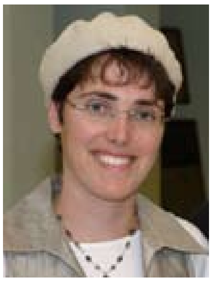
The usage of blastocysts for the purpose of stem-cell research has created heated debates throughout the western world, both on ethical as well as on religious grounds. It also prompted legislative and political controversies with very different solutions to the issue in various societies and countries. Currently, more than 20 countries have legislated lenient and non-restrictive laws allowing various forms of using stem-cells for research whereas less than 10 countries legislated prohibitive and restrictive laws.

The Catholics are strongly opposed to any form of destroying fertilized eggs, including for the research of stem-cells, based upon their dogma of ensoulment which occurs at the moment of conception. On the other hand, in Islam theology a fetus is regarded as human only after 3 months of gestation.

When examining the scientific aspects of stem-cell research from a Jewish point of view one ought to verify whether or not the net result will be beneficial to human being, and whether or not in the processes of developing this research there are any violations of halakhic rules. The answer to both issues is in favor of this research: It certainly will be very beneficial and from the Jewish position the in-vitro blastocyst 5 days old has no status of a human being, hence its destruction is not considered murder; and if the blastocysts used for stem-cell research are superfluous and unclaimed by its owners it does not have even a potential for life.

Effects of DBS treatment on personality of patients

Renana Eitan, Department of Psychiatry, Hebrew University
Hadassah Medical School, Jerusalem, Israel



Deep brain stimulation (DBS) is the most area specific method for stimulating the human brain. DBS uses an implanted electrode to deliver electrical stimulation to specific brain structures. While DBS is an approved therapy for severe, medication-refractory movement disorders, it remains investigational in neuropsychiatry. However, experience to date, though limited, suggests that DBS may offer a degree of hope to patients with severe and treatment-resistant neuropsychiatric illnesses, mainly obsessive-compulsive disorder and treatment-resistant depression.

DBS is a relatively new and exciting method which calls for further research and brings new hope for severe physically and mentally ill patients. As any new protocol, it should be performed cautiously, especially considering the potential vulnerability of mentally ill patients. The consent process should include discussion of what is and is not known about short and long term consequences of DBS. Awareness and sensitivity to the moral and ethical dilemmas, together with cooperation of experts from various disciplines and research centers, are a precondition for successful implementation of this almost science fiction method.

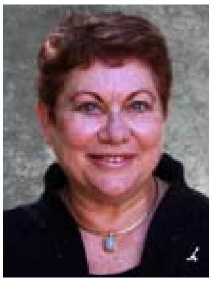
Ethical issues in neuroimaging research: Participants' perspectives

Elizabeth Peel, School of Life & Health Sciences,
Aston University Birmingham, UK

Neuroimaging techniques (e.g., MRI and MEG) are increasingly used in experimental research, but little is known about how participants' themselves experience these procedures. This study focused on participants' perceptions about neuroimaging scans and two emerging ethical concerns: the potential for raised anxiety prior to an MRI brain scan and incidental findings, that is, the possible identification of potential pathology in a scan conducted purely for research. Two sets of semi-structured interview were conducted: post-scan interviews with participants with prior experience of having a brain scan; and pre and post scan interviews with 'naïve subjects' - participants with no previous experience of being scanned. The pre scan interview focused on their expectations of MRI, and post scan interviews allowed them to reflect retrospectively on the experience. Findings show that participants can become anxious before a scan and the protocol for managing incidental findings is unclear. Themes are: ongoing interaction between experimenter and subject; the nature of anxiety - latent or normative; anticipating the MRI experience; expectations of a diagnosis/clean bill of health; submitting to a medicalised context and MRI scanning as a bodily encounter. The 'naïve subjects' lacked a frame of reference in which to contextualise their expectations and therefore felt ill-prepared. Many drew on a medical narrative because of the familiar medicalised connotations of neuroimaging. Recommendations include a routine dialogue between researcher and participant to clarify information, and offer a 'virtual tour' or sensory 'taster' of the neuroimaging experience as part of the consent procedure. Through research of this kind, which prioritises the 'insider's perspective', neuroethical guidelines can incorporate the experiences of those who have been scanned.

The neuroethics of brain research

Hermona Soreq, Faculty of Science, Hebrew University, Jerusalem, Israel



Current brain research is a powerful tool, with possibly severe implications to those who were the subjects of such research. There may hence be a conflict of interests between the wish to publish brain research findings and the necessity to conceal such findings. Today's ethics of academic research call for all scientists to freely and openly publish their work, so that it will get to be known. But in certain cases, immediate publicity is not advised. Examples include cases when keeping silent provides an important advantage to the scientist's society (well known cases like that, albeit in other fields are those of Arachaemedes, Galileo and to a certain extent Einstein; in brain research, Ivan Pavlov's name comes to mind); also, publishing should be controlled when someone's rights might be deprived if findings are known (examples include genotype studies predicting behavioral impairments), or if such publication may empower unknown people or organizations, with the risk of subsequent damage (such as the DNA sequence of a neuro-lethal agent). Finally, it would be unethical to publish one's findings when delaying publication (for example, of the discovery of a new therapeutic agent for acute stress)increases the prospects of utility, for the benefit of society at large.

Why and how to teach medical ethics

Alan Rubinow, chairman of the committee for teaching medical ethics in the Faculty of Medicine. Hadassah University Hospital Ein-Karem, Jerusalem, Israel

Many medical schools offer students courses in bioethics, communication and ethical conduct in pre-clinical years. clinical ethics is instructed through frontal lectures, seminars, role playing using simulating patients, and case studies. Objective: To determine whether med-students, on their first internal medicine clerkship, can detect, analyze and apply basic bioethical concepts at the bedside. Methods: Following a 35-hour course in clinical ethics, fourth-year students began first clinical rotation on a general medical ward. After eight weeks, students required to describe a patient where an ethical/professional problem was identified, presenting the conflicting ethical principles and suggesting way(s) to resolve the dilemma. Reports were categorized according to primary issue raised: ethical, professionalism and medical students' role. Reports were presented to peers (20 students) and facilitator.

Results: Between 2001-2007, 228 students participated in the program. 204 students (89%) submitted relevant case studies. 90 students (37%) presented an ethical dilemma; autonomy, end of life issues, resource allocation, ageism, decision-making capacity, surrogate/caregiver/family interaction. 61 (30%) presented a professionalism problem; confidentiality, truth telling, paternalism, arrogance, disrespect for patients, whistle blowing. 53 students (23%) emphasized ethical issues specific to medical students; terms of introduction, disclosure of information, practicing skills (blood drawing), presumed consent, intimate physical examination etc. Cases presented reflect complex, conflicting issues and show how students demonstrate insight and observational skills.

Conclusions: Medical ethics can be taught and assessed. Case-finding is a useful method examining the ability of students to apply bioethical concepts and identify problematic issues at the bedside. It promotes empathy, awareness, moral reasoning and maturity at a crucial stage in the professional development.