

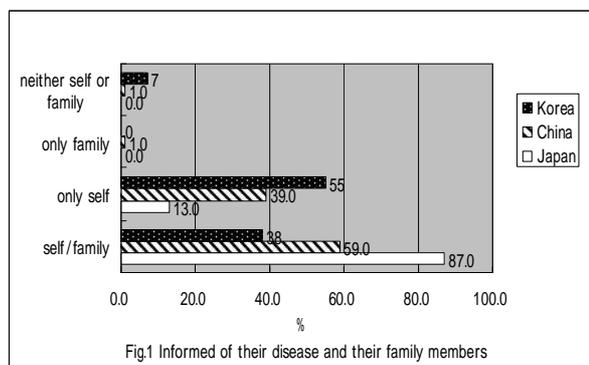
## Truth Telling about Terminal Cancer Patients: Differences in the Views on Life and Death in Japan, China, and Korea “The Ethical Consideration”

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The research study used a questionnaire for university students in Seoul, Korea in 2006, in Beijing, China and in Fukuoka, Japan in 2008. University students from three countries were asked some questions regarding their attitude toward truth telling of a malignant cancer and to answer in a five-point scale.

As a result, Japanese and Chinese students had a relatively high number of similarities. The majority of the students in both countries—87% of Japanese and 59% of Chinese—desired truth-telling to themselves and their families. 13% of Japanese and 39% of Chinese students wanted to know their own information by themselves but did not want their family members to be informed. These tendencies are quite similar to those in our study conducted in 2006 for Korean students. Both Chinese and Korean students did not want their family members to share the true information of their condition because they did not want “to be looked at while dying” and “to look at a dying person” (Fig.1).

This tendency of avoiding telling the true information to their parents was especially quite high among Korean female students. In making up questionnaires, we had thought such sentiments about “to look at death,” “to



be looked at,” and “what comes after being looked at”—those related to the “look,” as peculiar to Japanese. However, we found that such sentiments can be shared with Korean and Chinese.

This pilot study is just beginning to explore finding opinions regarding one of many different kinds of bioethical issues among East Asian countries. Through the accumulation of further empirical research data, we would like to compare values on bioethical issues and find certain similar or different values to promote their communication and mutual understanding of the viewpoint of life and death among East Asian countries.

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## *Reports from around the World*

### **Peking University Institute for Medical Humanities, China**

The first two weeks of November 2010 was a hectic but exciting period of time for the Peking University Institute for Medical Humanities (PKUIMH). The 5<sup>th</sup> Sino-U.S. Medical Professionalism Conference was held from Nov.1-2 on the campus of Peking University Health Science Center. Themes of the conference included new development in medical professionalism, medical professionalism and health policy, and conflict of interest.

From Nov.5 to 7, The Beijing Forum 2010 was held at the Diaoyutai State Guesthouse, the main campus and the Health Science Center campus of Peking University. This year a sub-forum “Health for All: Conscience and Commitment of Medicine” was co-hosted by the PKUIMH and the School of Public Health of Peking University. It was the first time for the PKUIMH to host a sub-forum of the influential Beijing Forum. Please see the summaries of each panel session below.

From Nov.7 to 12, the PKUIMH hosted the 3<sup>rd</sup> Peking University Medical Humanities Week. Active student involvement was the eminent feature of this year’s Medical Humanities Week. An exhibition entitled “Beauty in Medicine” showcased students’ paintings, photographic works and calligraphy. Students of medicine and allied health sciences presented beauty in medicine from their own perspectives. Students also stages some short English plays they wrote themselves, and provoked

discussion on the healing effects of love and care, stigma of HIV/AIDS, conflict of interest in medical research, as well as the money issue in health care. Apart from that, many students—both undergraduates and graduates—took part in the translation contest of philosopher Hans Jonas’s work on mortality.

An art exhibition called “Medicine on Canvas” attracted the attention of everyone entering the hall of the Yifu Building. Reproductions of oil paintings by 17<sup>th</sup>-19<sup>th</sup> century western painters featuring the healers and the healing process provoked reflections on the nature of medicine and the flaws of modern medicine.

Like the first two Medical Humanities Week, public lectures by famous scholars was a big attraction to students. The speakers are Professor John Harley Warner from Yale University, Professor Jingbao Nie from Otago University, New Zealand, Prof. Huang Jianshi from Peking Union Medical University, and Prof. Wang Yifang from PKUIMH. Their topics are following:

“The Visual Culture of Modern Medicine: Image and Professional Identity in America” (Warner); “Japan’s Wartime Medical Atrocities and International Aftermaths: Ethical Reflections” (Nie); “Individual’s Pursuit of Health” (Huang); and “Medicine on Canvas” (Wang).

#### **Beijing Forum:**

#### **The Panel Session on Health for All: Conscience and Commitment of Medicine**

##### **1. The First Session**

The Medical Panel Session of Beijing Forum was initially held in Diaoyutai State Guest House on November 5<sup>th</sup> 2010, Beijing, China. The theme of this sub-forum is “Health for All:

Conscience and Commitment of Medicine,” which will be discussed in four sessions for three days. Each session will be further divided into two phases. Experts from the United States, United Kingdom, Australia,

Japan and other nations will contribute their researches and thoughts to have a heated communication and discussion focusing on the main topic.

The first session was presided by Professor Wang Debing, Vice President of Chinese Medical Doctor Association (CMDA), former President of Beijing Medical University and former secretary of the Party Committee of Peking University. This part was focused on three main topics, which are “global health,” “medical humanities,” and “health and its distribution.”

Professor Elizabeth Fee, Chief of the History of Medicine Division, National Library of Medicine, NIH, gave a speech entitled “Using History to Make a Difference in Global Health,” in which she introduced free resources in the library and presented how to communicate and interact with the public health audiences by using these resources. She introduced the current exhibition “Against the Odds: Making a Difference in Global Health” and emphasized that the goal of such an event aimed at deepening the understanding of global health issues and inspiring the audiences to “make a difference” by the exhibition.

For the global health issues, Professor William Schneider from Indiana University, USA, presented his opinions from another perspective. In his report “Medicinal Humanities, Global Health and Philanthropy,” he revealed the background of international health philanthropy, the advantages and disadvantages during its development. He thought that global health will provide every member in the society with a chance to attend cross border care. The opportunities provided by the international health philanthropy are actually a reaction to the international health need, as well as an echo of medical humanism.

Humanism was warmly discussed in this session. Professor Zhang Daqing, from the Institute for Medical Humanities Peking University gave a speech on “Medical

Humanities Education in China: PUHSC’s New Experiment,” in which, he outlined the historical background of medical humanities education in China and concentrated on the practice and educational concepts of Peking University Health Science Center (PKUHSC) as a case study and experience sharing. In the presentation, Prof. Zhang analyzed the necessity and challenge of medical humanistic education and introduced the establishment and development of the principles: History of Medicine, Dialectics of Nature, Medical Ethics, and Medical Psychology etc. He emphasized that PKUHSC’s experiment on persistent, integrated and in-depth medical humanities education will offer valuable experience to the medical education reform.

Around humanism, Professor Du Zhizheng from Dalian Medical University gave a speech titled “Capital, Technology and Humanistic Medicine.” He mentioned that there is a loss of balance between medicine and humanity. He analyzed the four negative impacts of the domination of capital in medical technology. The challenge to medicine, according to Prof. Du, is the domination of capital, which may change the fundamental property of medicine. He defined “humanistic medicine” and its objectives, and illustrated its value to resolve the problem of capital domination.

On the topic of health reform and the distribution of health resources, Professor Norman Daniels from Harvard School of Public Health shared his opinions: “Justice and Health: Implications for Health Reform,” in which, he argued that society has the obligation to protect the opportunity range of individuals by promoting and protecting health. It means the health policy must pay enough attention to the fairness of health distribution. He revealed the importance of equality in promoting health and put forward the implications for health reform, including adequate protection against risks, universal coverage, broader justice in distributing determinants of health, and special instance of rights to fair equality and accountability for reasonable entitlements. He

thought that the key step to health reform in China is priority setting process for expanding benefit packages.

On health equity, Prof. Qiu Renzhong from the Institute of Philosophy, Chinese Academy of Social Sciences emphasized the importance of equity in health care from another perspective. His speech, "Health Equity and Right-Based Approach to Health," presented two approaches. One is biomedical or technological approach. By analyzing, he pointed out that biomedical approach to health is inadequate and thus the second approach, the right-based approach to health must be applied.

## 2. The Second Session

On the morning of November 6<sup>th</sup>, the Medical Panel Session or the second session on Medicine of Beijing Forum was held in the Auditorium in Peking University Health Science Center (PKUHSC). Five experts discussed from diverse perspectives around "reconstruction of the medical professionalism." This session was presided by Professor Cong Yali, from PKUHSC.

On medical professionalism, there was a heated discussion from both western and Chinese perspectives including both the modern understanding and traditional thinking on this issue.

Professor Cong gave a speech titled "Improve Medical Professionalism in both China and US: Cooperation Perspective." She introduced the work done by the Joint Center for Sino-US Conference on Medical Professionalism in the recent five years since its start. And she presented the different situations in both countries including differences in the system, idea and function of associations, of the government and of the university entrance system etc. Professor Cong analyzed the strategies for cooperation and suggested what can be borrowed and what cannot. She pointed out that the U.S. has plenty of Conflicts of Interest (COI), which can be borrowed by China, and the United States can borrow the

experience of team work, self-cultivation from China.

Professor Daniel Wolfson from the U.S. side continued Professor Cong's discussion. He presented the speech on "Spreading the Principles of Professionalism: The U.S. Experience." Professor Wolfson introduced the defining professionalism in the U.S. and illustrated the gaps between physician aspirations and the actual behaviors. Then, he introduced the program of "Putting the Charter into Practice" and gave several typical examples.

On medical professionalism, President of Institute on Medicine as a Profession, Professor David Rothman from Columbia College of Physicians and Surgeons, put forward his presentation "Medical Professionalism in the United States Today: Challenges and Accomplishments." Professor David Rothman tried to explore the changing concepts of medical professionalism. He focused on whether professionalism has been revived or invented and whether the definition of the previous generations was lost in the modern times. The major attributes of professionalism including altruism, self-regulation, commitments to life-long learning, and advocacy were considered. Professor Rothman gave recommendations for professionalism that aimed at better understanding and further action in the future.

Professor Paul Braunschweiger, CITI Program Co-Founder, University of Miami, Ethics Programs discussed the topic on "Research Ethics Education Promotes Integrity in the Research Enterprise." He first defined integrity and emphasized its importance in research. He mentioned that "the ethical foundations for trust are based on Education." Professor Braunschweiger focused on introducing CITI program, which refers to the Collaborative Institutional Training Initiative. The aim of CITI program is to promote the responsible conduct of research by all members of the research team. He introduced what

CITI program is and how institutions use this program. He also mentioned about the situation of CITI International and CITI-China Initiative.

Besides the discussions from western perspectives, Professor Ling Feng from International Neuroscience Institute of China presented “Being a Great Doctor Seeking Perfection and Honesty,” in which she introduced the traditional Chinese understandings and philosophies to medical ethics. She explained “Ren Zhe Ai Ren” (human-heartedness consists in loving others), “Zhong Shu Zhi Dao” (do not do to others what you do not wish yourself) and “Zhong Yong Zhi Dao” (it is upon calamity that blessing leans, upon blessing that calamity rests). She mainly introduced the concept of “autopoiesis” in medical practice for the doctors. She explained the meaning of “Da Yi Jing Cheng” word by word from the traditional Chinese culture and philosophy. She emphasized that “the weight of your life is just how heavy the life of the patients” and said that this is the approach and bridge from the so-called “cold science” to warm humanitarianism.

The second half of morning session was chaired by Professor Allan Cripps, Pro Vice Chancellor (Health) of Centre for Medicine and Oral Health at the Griffith University, Queensland, Australia.

Health care system is facing lots of new challenges for the population aging problem and more health service needs with society development. How to build an equal, effective health care system that providing high qualified services has become the key question that people all over the world are working on.

Professor Carol Brayne from the University of Cambridge, Director of the Institute of Public Health, made a speech on “the Advantages and Disadvantages of the UK Health Care System: a Public Health Perspective.” She presented the fundamental principles of health care system-NHS, its sustainable development

process and the major characteristics. The UK model was based on primary care, which made the health system high qualified and equal. She talked about several challenges that they were fighting against, which including ageing population, funding division between health and social care, technical and pharmaceutical advances and so on.

Professor Meng Qingyue from China Center for Health Development Studies (CCHDS), Peking University addressed the forum with the topic: “Universal Health Care Coverage in China: Challenges and Opportunities.” He analyzed the situation of universal coverage in China using existing data and raised challenges and opportunities for achieving the health systems reform aiming at achieving universal health care coverage by the year 2020. He analyzed the universal health care coverage with three dimensions according to WHO’s analytic framework which include breadth (population coverage), depth (service provision), and height (financial protection). He pointed out that there were existed disparities in service provision among regions, rural and urban areas, and different population groups. Therefore, improving the existing health financing system, advancing provision of public health care, and strengthening interventions for priority public health problems were the essential issues that appealing actions.

Professor Mark Harris from the University of New South Wales, Executive Director, Centre for Primary Health Care and Equity, talked about “the Systems and Strategies for the Prevention, Early Detection and Management of Non-Communicable Disease in Primary Health Care in Australia.” In Australia, over 80% of elderly patients suffered from at least one chronic illness. Chronic long-term conditions placed increasing burdens on Australia’s health system and wider economy. He talked about the development of chronic disease prevention, presented five preventive systems and their four goals and objectives. He also pointed out that voluntary enrolment of patients with chronic and integrated primary

health care centers were two key points of the primary health care strategy for chronic diseases.

Professor Fu Hua from the School of Public Health, Fudan University made a speech on “Meeting Challenges of Non-Communicable Diseases from Ageing Society with Innovative Approach.” He pointed out that China was facing the challenges of non-communicable diseases (NCDs) due to ageing and other risk factors, and conducted an approach of group visiting combining with self-management of patients with NCDs under the context of Chinese culture and co-shared duties through participation to explore the solution of the challenges. According to the community randomized designs he used and other data, the approach could change behaviors for self-management, enhance self-efficacy, improve health status, emotions, and the quality of life, as well as reduce utilization of medical services. He also made recommendations on the health system reform about the dissemination of this innovative approach. The morning session was ended with heated discussion and communication. More topics will be presented in the afternoon.

### 3. The Third Session

On the afternoon of November 6<sup>th</sup>, the Medical Panel Session, the third session on health and medicine of Beijing Forum, was held in the Auditorium in Peking University Health Science Center. Five experts discussed medical humanities from different perspectives. This session was held by Professor Zhang Daqing, Director of the Center of the History of Medicine, Peking University.

Professor John Warner from Yale University illustrated humanism from the perspective of medical history. He presented “The Humanizing Power of Medical History: Responses to Biomedicine in the 20<sup>th</sup> Century United.” He first introduced the background of biomedicine by the start of the 20<sup>th</sup> century in the USA, when the new experimental sciences were transforming medical knowledge, practice

and institutions, which offered the profession both a technical tool and a powerful cultural tool. He noted that it is remarkable that at precisely the medical institutions where emergent version of scientific medicine was entrenched, some doctors began to warn that the same allegiance to science was endangering humanistic values which were fundamental to professional identity, the art of medicine and cultural cohesion. He explored the ways that physicians treated medical history as a vehicle for re-humanizing modern medicine, a counterbalance to reductionist hubris in the individual physician and a cohesive force binding the splintering tendencies of an increasingly specialized medical world.

On “Eco-sexology: A New Paradigm,” Professor William Granzig, President of the American Academy of Clinical Sexologists, introduced a new model as “Eco-Sexology.” He introduced the connotation of eco-sexology. He mentioned that such concept deals with an examination of the sexological problems and trends that confronting a society, eco-sexology is a study of the sexological relationship between man and society, and whether man utilize the changes in social customs, ecological, emotional and intellectual environments to built a new world. He stated that the education of sexuality in our society is the instrument which provides men with the knowledge for shaping individual lives, economic development and political socialization. He emphasized that the study of eco-sexology is predicated on the thesis that man must have an understanding of the environment in order to effectively deal with societal changes and what effect these dynamic changes have on individuals, couples and society, and what effect these sexologists have on the changing environments of man. He concluded that the society must depend on educational institutions as the agents of change to build a paradigm of the attitudes which will help develop broader outlines of social goals that will become social policies of the culture. The task of the educational institutions to enhance an educational philosophy today will become the socio-political policy of leadership

which will represent the new paradigm of eco-sexology.

Professor Nikolas Rose, Director of the BIOS Research Center, London School of Economics and Political Sciences, gave a speech on “Personalized Medicine: Promises, Problems and Perils of a New Paradigm for Healthcare.” Personalized medicine is widely discussed in recent studies. He pointed out that a new paradigm for medical care, personalized medicine, is emerging. He argued that the future of medicine should and will be PPP which means “personalized, predictive and preventive.” He also critically assessed the promises made for personalized medicine, discussed some of the challenges for health policy and considered the social and ethical implications for moving medical care toward such a personalized and individualized model.

On medical humanities, Professor Lyndal Hooker, Director of Medical Humanities Center for Values, Ethics and the Law in Medicine, the University of Sydney, presented “Exploring Difference and Otherness in Medical Humanities,” in which she mentioned about the texts used in medical humanity programs tend to normalize the field around an Anglo-European literature, set of patients and practitioners and history, concepts and experiences. She believed that medical humanities can be possible to even unintentionally contribute to the construction of difference and otherness in medicine and health care.

In terms of “difference,” Professor Nie Jingbao, from Bioethics Center, University of Otago, New Zealand, put forward his understanding between China and the West. He raised cases prescribed in ancient Chinese medical books that in contrast to contemporary Western practice, medical professionals in China customarily withhold from patients crucial information about terminal illness, a “cultural difference” view of truth-telling and informed consent has developed. He argued that China had a well-established but forgotten tradition of

medical truth-telling. In conclusion, Professor Nie reminded the scholars that the history is more complex than we have imagined.

The second half session on this afternoon was presided by Professor Wang Peiyu from the School of Public Health Peking University. Dr. Ding Ningning, Senior Research Fellow from Development Research Center of the State Council, P. R. China made a lecture on “Views on Current Health Care Reform in China.” The Chinese government has increased its financial input to the health sector, but there were still some remaining issues about the health system that merit our attention. He pointed out the key areas of current health system reform and the main principles: serious diseases or common and frequently-occurring diseases, strategies for solving the problems of healthcare security for migrant population, and the division of responsibilities between government and market in the health care area. A new understanding of health and diseases in China goes that “diseases could be cured, but lives might not be saved.”

Professor Zhang Xiulan from the School of Social Development and Public Policy, Beijing Normal University, delivered the speech on “the Impact of Shenmu Universal Health Insurance Scheme on Health, Poverty and Rural Health System.” She described the Shenmu model and discussed the key policy implications of the Shenmu health reform for rural China’s health care system. She pointed out that the government should be buyer of the healthcare service and healthcare insurance. The whole health system should be a good collaboration of all three roles which are the providers (health care institutions such as hospitals), buyers (the government) and the consumers (the whole population). It means that the health system benefited every role involved.

Professor Derek Morgan of Health Care Law & Jurisprudence, University of Sheffield, made a speech on “Civic Constitutions and Human Health.” He pointed out that the connections between health and wealth were well remarked.

Both health and welfare engaged essential philosophical questions and disclosed moral and ethical dilemmas. A just system of health care allocation should be backward-looking, concerning about what individuals have done in the past to safeguard, preserve or damage their own health so that the state should reward (or discipline) them in the response. He meld these discussions of responsibilities, values and values on examining, perhaps somewhat cursorily here, as one consequence of the displacements of the nineteenth and twentieth centuries. Therefore, he urged that the debate about 'new citizenship,' should additionally involve an investigation of the sense of strong democracy.

Professor Huang Jianshi of Epidemiology, Dean for the School of Public Health, Peking Union Medical College, gave the speech titled "We Need to Manage Our Health Actively Instead of Waiting Diseases Passively." He pointed out that the greatest challenges to the human health come from the chronic non-infectious diseases today. The prevention and control of chronic diseases under the bio-medical model (characterized by single etiology-single disease, pathology of diseases originated from cells) seems to be powerless. He analyzed why the out-of-the-date biomedical model is still dominant China's health care system. Considering the newly released China Medical Reform Implementation Plan, he offered advices about how to successfully make the transformation from the old biomedical model to the new bio-psycho-social-model, which is the health behavior management.

The last speaker of today's session was Professor Keith West of International Health and Ophthalmology, Director of Program for Human Nutrition, Department of International Health, Bloomberg School of Public Health, Johns Hopkins University. He gave a speech on "Micronutrient Deficiencies: Nutritional Inequity and Public Health Consequence in the Developing World." He emphasized that micronutrient deficiencies increased with inequity in socio-economic status and may have

both short and long-term effects on survival, health and function on early life. There were several approaches to prevent micronutrient deficiencies and many of them had been proved to have short and long-term public health benefits. He suggested that approaches for prevention should be adapted to resources in a country and it was also one of the most progressive approaches for bringing equity to the poor, saving lives and building human capitals.

#### **4. The Fourth Session**

On the morning of November 7<sup>th</sup>, the Medical Panel Session, the fourth session or the last session on health and medicine, was held in the Auditorium in Peking University Health Science Center. Four experts raised speeches on medical humanities. This session was presided by Professor Nikolas Rose.

Professor Heikki Kallio from the University of Turku, Finland presented "the Oriental-Western Dilemma: From Isolated Pathways to Network for People." He shared his understandings about consumer protection as a global issue, to the rules of nature and the rules of man. He emphasized that safety limits are not unambiguous and put forward the way to equality.

Professor Kiichiro Tsutani from the Department of Drug Policy and Management, Graduate School of Pharmaceutical Sciences, the University of Tokyo presented "History of Globalization of Traditional East Asian Medicine and Emerging International Standard Setting: from Cultural and Ethics Point of View." He first introduced the situation of ADR reports in China and pointed out its sharp rise since 2000. He introduced briefly the development of medicine especially the traditional medicine in China of the second half of the 20<sup>th</sup> Century. He then pointed out the problems during the development. One is the need of international standard name and code because one formula may have multiple names in different nations. He examined the work done by the WHO in terms of standardization.

He concluded that from international health perspective, Traditional Eastern Asian Medicine (TEAM) became a part of the intellectual property business. Nationalism is needed, but consumers should be protected. He also concluded that evidence on safety and efficacy, quality assurance and cooperate social responsibility (CSR) is needed as an international export item.

Professor Claudia Wiesemann from the Department for Medical Ethics and History of Medicine, Goettingen University Medical Center shared her understandings about Children's rights. In the presentation "Children's Rights in Medicine, Child Interests and Family Privacy," she illustrated the case of a 13-year-old girl, Hannah Jones, who suffered from leukemia firstly refused doctoring but later changed her mind and eventually successfully receive a donor organ to recover. She raised the thinking and rethinking of children's rights.

Dr. Angela Woods from the Center for Medical Humanities, Durham University, gave a presentation on "The Limits of Narrative."

She raised the research question that how far medical knowledge and capabilities should inform or shape the conceptions of human flourishing and what roles medical humanities should play for improving our lives. She mentioned that narrative in medicine is held to provide privileged access to the subjective experience of illness and provided insight into the experience of medical professionals, careers and family members and to be therapeutic and transformative. It is held to offer new methodologies for qualitative research into the illness experience, and to provide a foundation for a new ethics and politics of healthcare. She also introduced Galen Strason's theory "Against Narrativity" and its critique.

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## Centre for the Humanities and Medicine (CHM), The University of Hong Kong, Hong Kong

This year the Centre has sponsored numerous conferences, lectures and research seminars focused on its core Research Themes. The Centre's Health Communication cluster, led by Dr. Olga Zayts, was pleased to be one of the sponsors of the '9th Asia-Pacific Conference on Human Genetics' between November 30<sup>th</sup> and December 3<sup>rd</sup> 2010. In recent years, significant advances in genetics and genomics have been made at the scientific front. With the development of new technology and understanding of human diseases, these advances have paved way for major impacts in healthcare. The application of knowledge gained at the laboratory bench and clinical settings have been successfully transferred to diagnostic, therapeutic and preventive care. This trend is not only found in specific regions

of the world, where medical and scientific development is more advanced. Instead, it has become a pervasive phenomenon throughout the whole world. Genetic and Genomic Medicine has come of age. The Asia-Pacific Region has not been left behind in this tide. For the past couple of decades, countries and areas in this Region have taken on the challenge to develop human genetics and its application. A network of collaboration has also been formed among academic centres, professional societies and various types of organizations in this Region.

The Centre was also a co-sponsor of the 'Peaceful Mind, Joyful Heart: A Day of Mindfulness for Health Care and Helping Professional' in November, when HKU

welcomed Zen Master Thich Nhat Hanh to Hong Kong.

In addition, CHM partnered with the HKU-Pasteur Research Centre to organize a symposium on 'The Nature of Altruism' in the Li Ka Shing Faculty of Medicine on November 23rd. Participants included Professor Oren Harman (Bar-Ilan University, Ramat Gan, Israel), author of The Price of Altruism: George Price and the Search for the Origins of Kindness (W.W. Norton, 2010) and Dr. Thomas ST Chan (World Vision).

Next year is set to be equally busy with a series of cross-cutting research workshops and conferences, beginning with 'Disease and Crime: Social Pathologies and the New Politics of Health' in April, which will explore the historical equation of crime-as-sickness and infection-as-wrongdoing; a keynote speaker will be Mark Seltzer, Evan Frankel Professor of Literature at UCLA and participants will be drawing upon case studies from China, Taiwan and Korea, as well as the US and Europe.

One of Centre's core missions is to bridge the divide between the Faculty of Arts and the Li Ka Shing Faculty of Medicine, and in so doing to reconnect academic study with the University's worldly remit. With this aim in mind, the Centre will launch the CHM Humanitarian Programme in May 2011 when Didier Fassin, CHM Visiting Research Professor, arrives at HKU on the first of his visits from the Institute for Advanced Study, Princeton and the École des Hautes Études en Sciences Sociales, Paris. In recent years Humanitarian Studies have developed as a crucial area of inquiry, in large part as a response to the complex situations arising from wars, conflicts and natural disasters. The aim of the CHM Humanitarian Programme is to restore the 'humanitarian' to the humanities, as well as 'humanizing' medical interventions, thereby providing a unique opportunity to integrate medicine and the arts, and in so doing help to build a more secure and humane environment.

Within the Li Ka Shing Faculty of Medicine, the Medical Humanities Taskforce has also been active this year in planning for the reform of HKU's clinical curriculum. Supported from grants from the Development Fund for Medical Humanities, a number of cross-disciplinary medical humanities initiatives are being piloted, including courses on: 'Exploration of suffering and wellbeing through visual narratives of illness,' 'What makes for a better doctor and good medical practice? - Perspectives from Film and Book Narratives' and 'Body-mind-spirit integrative training in medical school for stress management and prevention against junior physicians 'burnout.'

Finally, as part of the Centre's commitment to outreach work, CHM is currently developing a major art project with the Hong Kong Museum of Medical Sciences. The aim is to promote public debate on culture, community, wellbeing and health. The new initiative follows from the success of the multi-media exhibition 'HOPE & GLORY' in April and May 2010 at the ArtisTree, which was co-sponsored by CHM and was visited by some 60,000 members of the public.



Prof. Françoise Barré-Sinoussi, recipient of the 2008 Nobel Prize in Physiology or Medicine, in discussion with Dr. Robert Peckham (Centre for the Humanities and Medicine) following Prof. Barré-Sinoussi's delivery of the second Centenary Distinguished Lecture at HKU on November 22<sup>nd</sup> 2010.

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## The Institute for the Medical Humanities, University of Texas Medical Branch at Galveston, USA

As recent news of the Institute for the Medical Humanities (IMH) at University of Texas Medical Branch (UTMB) at Galveston, Texas, U.S.A., I write about one of the newest members of our associate faculty, Mr. Dax Cowart. IMH may not be located in East Asia, but I think the name Dax Cowart is well-known to the people there engaged in medical humanities, health-care ethics, and bioethics.

The medical humanities has been actively involved in responding to early bioethics cases, which were unprecedented at the time but have since become classic cases. Humanities study illuminates the moral and human values and virtues with the knowledge and reflection traditionally proper to each humanities discipline. One such case is that of Donald (Dax) Cowart. In 1973 Mr. Cowart was in an accidental propane explosion in rural East Texas, which killed his father and gave Donald third-degree burns over 67 percent of his body, left him blind, and deprived him of the functions of his hands. In the ER Cowart expressed his wish to die without receiving any medical intervention. However, his treatments continued against his will. After he was transferred to the UTMB hospital, he consistently requested to be free from the excruciatingly painful treatments so that he could go back home to die. The psychiatrist who was sent to assess his mental capability agreed that Donald was fully capable of making a rational decision. Finally, Donald agreed to continue to receive treatments and get a surgery that would restore some of the function of his hands. To advocate the respect for the patient's request to die, he went back to law school, became certified as a lawyer, won his first case as an attorney, and has been active in lectures and meetings to raise awareness of the patients' rights. Partly because of the influence of the two powerful documentary films, [Please Let Me Die](#) (1974) and [Dax's Case](#) (1984), Cowart's case is still taught in the education of medical ethics for health-care

students and practitioners. Exploring the many conflicts involved in his case has led to deliberation and alteration in the ways of thinking about what health professionals are supposed to do for the best interests of the patient. The conflict between medical paternalism and the patient's autonomy is only one of the issues to address.

UTMB has invited Dax every year to address medical students in the Humanities, Ethics, and Professionalism (HEP)—summer course in the School of Medicine. In the past years I have had extraordinary opportunities to hear him in person and learn more about his life story when I served as a facilitator for small groups of medical students in the HEP sessions. Many students seem to have a strong resistance against terminating the life of a person who is young, mentally intact, and not in the irreversible or terminal condition. The finality and irreversibility of death weigh with them. Not a few argue that Dax must be in the state of shock after the horrific accident that it could be justifiable to override his wish to die before the physician's duty to treat. However, some students express their intent to respect the patient's autonomous decisions based on his rational mental state.

Anyone who has seen the film [Please Let Me Die](#) would be stunned at the atrocity the accident left on Dax's entire body. When forced to be immersed in the Hubbard tank to keep from infection and applied medication and bandages by the staff, he looks like a withered and stiffened stick. After a number of skin grafts and reconstructive surgeries, he looks normal when he is on the stage. His voice is strong and articulate. It is little wonder that some students and practitioners want to celebrate the miracle modern medicine could perform. Nevertheless, to hear him in person saying how difficult it is to live day by day as a blind person with limited hearing ability, inability to meet his very basic needs without

aid, and no fingers that could allow him to read Braille, one also has to think of the cruelty medicine inflicted on him. Dax is today glad to be alive, but remains persistent in his belief that he had the right to refuse treatment and to be allowed to die. Not only students but also people who have the privilege to be in his company are forced to confront this apparent contradiction. I am amazed at his presence as an example of how a single person could help influence and transform attitudes and thoughts as well as practices in medicine and society.

I would like you the reader of the Newsletter to let me know if the case of Dax has been taught at your institute or others in your countries. I think that Dax is an iconic figure that bridges differences between the East and West with the human predicament that speaks up in his humanistic language.

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One of the biggest themes for us in 2010 was culture—and responsibility. This theme was sustained in two large and highly successful events—the screening of Prof Sidney Bloch’s film about his return to South Africa to apologize to the black medical students in class for not actively opposing the discrimination they experienced, and the public lectures given by Dr. Esther Sternberg, whose research has demonstrated links between space, architecture and health. But this theme also came more to the fore in our teaching new courses in literature and medicine, in the projects undertaken by medical students, and in many interactions with colleagues locally and around the world.

It seems surprising that culture is not, conceptually, of more significance in medical humanities programs, since they are chiefly composed of the arts and letters that are usually identified as ‘culture.’ (In Australia, we self-mockingly describe a trip to the art gallery as ‘getting kulcha’). I have been increasingly interested in what culture is and what it does for two reasons this year. The first is the question of how to navigate culture in health care, in a nation where both patients and their (often foreign-trained) physicians come from a great variety of different backgrounds. When faced with the complexity of many cultures and one’s own unending ignorance of most of them, most physicians take the easy way out and say they

simply treat everyone ‘equally.’ That this stance, however morally admirable, is but an avoidance of the issue is indicated by (a) the way growing social inequities make a mockery of any claims of equality in treatment (b) the way ‘equality’ tends to bulldoze over the differences that are in fact of primary importance to people and intrinsic to identity, and (c) the fact that both patients and doctors themselves don’t feel treated equally on the receiving end. Instead we need to help doctors see their patients, not just as ‘individuals,’ but as individuals defined and often constrained by cultures of which the doctor her or himself knows very little. The insight and compassionate perception so valued as one of the hallmarks of a humanistic doctor may often rest on the cultivated skills of recognizing and asking about these marks of culture in their patient’s views and emotional needs.

Since most Australians come from somewhere else, and since a fairly high percentage of practitioners today are specifically from Asian and Indian backgrounds, it seems natural to me to look to their countries of origin for ways of exploring humanism and culture in medicine. After all, what long and sophisticated cultures and histories of health care these countries have! Hence my excitement about the number of new medical humanities programs developing in our region. The highlight of my year was attending the Beijing Forum in

November, and having the opportunity of meeting colleagues from China and Hong Kong, as well as those from the USA and UK. This meeting highlighted my hope that the take up of medical humanities programs from around the world will alter what medical humanities actually is. One of my hopes for 2011 and beyond is that all of us in the region might be able to share resources so that we can build a reservoir that represents many cultures, for us all to draw from—and I would like to take this opportunity of officially extending a warm welcome to anyone who can possibly come to visit us in Australia, and to hope for a regional meeting at some point soon.

The terrific collegiality of the Beijing Forum and surrounding meetings allowed a frank discussion that was critical of the medical humanities, too —the sort of discussion that feels like an unthinkable betrayal when you are defending their importance to unsympathetic Deans or to epidemiologists and surgeons with no vision beyond what is strictly quantifiable. But at the Forum one could wonder aloud about what good reading Tolstoy actually does, and whether in fact he doesn't more represent the arrogance of a highly privileged (and very 'western') cultural elite than a humanistic influence on young doctors, and whether narrative really can do all the stuff we think it can anyway (thanks to my colleague from Durham, Dr. Angela Woods, for articulating this one).

It was very good for me to have to revisit some basic arguments, such as 'what good is art anyway?'. These are all the more important when teaching medical students, who in my experience are focused on whatever is pragmatic and instrumental and not very welcoming to anything more 'wishy washy.' Medical students in Australia today did not get a 'classical' education, unlike the majority of doctors who began promoting the medical humanities 30 years ago. Instead they got a new digital media and the era of economic

rationalism, which together did a very good job of leaching a lot of the meaning and value out of the world beyond that which is measurable in outcomes and benefits. I have found that I convince most of them by really hardheaded rigorous scholarship, of the kind found in bioethics, history and philosophy of science, and that they are then willing to contemplate exploring all those elements of the medical humanities that are more vested in the impulses and passions of the creative arts. The ten medical students from Korea that I am currently teaching are much the same.

These remain the issues for me to wrestle with in 2011, and, together with colleagues, to confront the movement between creative arts and analytic scholarship that can be so confronting within the medical humanities. In the meantime I continue to have the long-term goal of developing short intensive courses for continuing medical education and professional development. My aspiration is that such courses will become normalized in the future for health care practitioners (not just doctors) for two reasons. Firstly, this critical market is likely to maintain the stability of the medical humanities within the medical faculty and make it less liable to being sidelined by any aforementioned unsympathetic budget-slashing powers that be. And secondly, medical students just do not have the life-and-job experience that makes the lessons of the medical humanities meaningful. Instead, they are more likely to load up on moral aspirations that they then ditch in a socializing process of cynicism and pragmatism during the first 5 years or so on the job. The medical humanities comes into its own when those who grapple daily with the systemic as well as individual limitations of health care systems can find depth, sustenance, and strategy in its many diverse areas.

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## **Editors' Note:**

We are pleased to announce the publication of the third issue of the Newsletter of the East Asian Medical Humanities Network (EAMHN). EAMHN is a very young scholarly network established in Beijing in 2009. The primary mission of the establishment is to create a platform for academics, practitioners and institutions in the region for exchanging their views and experiences to promote East Asian as well as other parts of countries of the world.

In this third issue of the Newsletter, Masami Maruyama, Ph.D. of Kyushu University Japan introduces her pilot research study on truth telling of terminal stage cancer conducted in three countries: China, Korea, and Japan. She emphasizes that comparing values on bioethical issues and finding certain similar or different values is an important way to promote communication and mutual understanding of the viewpoint of life and death among East Asian countries.

Medical Humanities scholars from East Asian countries as well as from other parts of the world contribute to this issue to share their news and activities, too. The reports from Center for Medical Humanities of Peking University, China, Centre for the Humanities and Medicine at University of Hong Kong, Centre for Values, Ethics and Law in Medicine of University of Sydney, Australia, and the Institute for the Medical Humanities, University of Texas Medical Branch, USA are included.

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