“Decisions on Life-Sustaining Treatments in End-of-Life Care in Hong Kong: Challenges and Ways Forward”

Because of uncertainties in treatment outcome and emotions surrounding death and dying, decision-making on life-sustaining treatments in end-of-life care is sometimes difficult. The difficulties are greater if the patient is not competent. In Hong Kong, decisions for an incompetent patient are normally made by consensus building between the healthcare team and the family members in the best interests of the patient. However, this is not an easy process and is prone to conflicts. To improve the situation, the Hospital Authority issued Guidelines in 2010 to promote the use of advance directives (AD) in patients with advanced irreversible illnesses under the common law framework. While there is increasing acceptance of the concept of AD among the public, there are multiple challenges. These include legal uncertainties under the common law framework, conflict with the Fire Services Ordinance regarding duty to resuscitate of the ambulance crew,
knowledge and attitude regarding end-of-life care among healthcare staff, and a lack of understanding among the general public. The Hong Kong Government has just launched a public consultation on legislation on ADs. While this is a very important step forward, the Hong Kong public should understand the limitations of advance decisions refusing treatment. We are still waiting for the enactment of the Continuing Power of Attorney Bill to allow appointment of a healthcare proxy. Effort should be made to promote advance care planning with broader goals than just signing an AD. The public should also understand the controversies regarding signing ADs while healthy. The promotion of better decision-making should be part of the effort to promote better end-of-life care in general. The drafting of an overall policy on end-of-life care should be a next goal of the Hong Kong Government.

Chun-van TSE is a graduate of the University of Hong Kong in 1973. Dr. Tse has worked consecutively as the Department Head of the Medical Department of the United Christian Hospital (UCH), the Hospital Executive of UCH, and the Cluster Chief Executive of the Kowloon East Cluster of the Hospital Authority. After his retirement in 2005, he served as the chairman of the Hospital Authority Clinical Ethics Committee from 2005 to 2017, leading the Committee in drafting clinical ethics guidelines on end-of-life treatment decisions for the Hospital Authority. He is currently an honorary advisor of the Hong Kong Society of Palliative Medicine, a member of the Hospital Authority Clinical Ethics Committee, a member of the Ethics Committee of the Medical Council of Hong Kong, and an advisor to the Hospital Authority Task Force on legislation of advance directives.

Dr. Kin-sang CHAN

“Care Decision Issues in Palliative Care Patients – A Clinician’s Perspective in Hong Kong”

Despite modern medicine has successfully prolonged life, death is an inevitable destiny of mankind. New medical technologies bring new hope for cures but do not always alleviate the distress of patients with life limiting illnesses. A systematic review of 38 studies showed that an average of 33% to 38% of patients received non-beneficial treatments in the final 6 months of life. The modern hospice care palliative care movement was advanced a half century ago as an ethos based on compassion and care for patients and their families to relieve their suffering. Care at the EOL is an integral part of palliative care. Advance care planning (ACP) is a process that realised patients’ EOL goals. A recent systematic review on palliative care including 43 RCTs showed palliative care was consistently associated with improvements in advance care planning. Discussion on care decision issues is an operator
dependent process, which requires much sensitivity of the health care staff towards patient’s and family’s knowledge, expectation and readiness. A local study showed home care nurses often facilitate the dialogue of ACP. Other factors affecting the discussion of care decision issues include: hope vs futility of new drugs & technologies, different illness trajectories for different diseases, and early introduction of palliative care. Experiences in patients with advanced cancer, end stage renal failure, and advanced COPD will be shared to illustrate the complexity of decision process. Beyond advance care planning, palliative care aims at alleviating suffering by a holistic biopsychospiritual person-centred approach which hopefully brings a more peaceful final journey of life.

Kin-sang CHAN graduated in University of Hong Kong in 1981, with dual specialist accreditations in palliative medicine and respiratory medicine in Hong Kong College of Physicians. He was the past Chief-of-Service, and currently the Consultant of Haven of Hope Hospital.

He served in Hospital Authority as Co-Chairman of Central Committee on Palliative Care, and Chairman of Subcommittee in Palliative Medicine of Hong Kong College of Physicians. He is honored as invited author on Chapter of Respiratory symptoms in Oxford Textbook of Palliative Medicine (3rd to 6th edition-to be released). He enjoys serving the weak and the vulnerable.

Prof. Chih-hsiung CHEN

“Taiwan’s End-of-Life Legislation: How it helps and What Are the Challenges”

In Confucian societies, people tend to avoid the discussion on death matters with family members, let alone making advance directives to reject life-sustaining treatments at the end of life. Taiwan might be a pioneer in legislating the right-to-die with dignity among Confucian countries. As early as 2000, the Hospice Palliative Care Act was declared in Taiwan, which gives terminally-ill patients the options to forgo life-sustaining treatments. Furthermore, in 2016, Taiwan passed the Patient Right to Autonomy Act to enhance patients’ choice at the end of life and expanded the coverage to certain types of non-terminally ill patients.

This presentation is divided into three sections. First, this presentation analyzes the sociocultural emphasis on family unity in East Asia and attitudes toward death in East Asian cultures, and then the methods adopted in Japan and South Korea of solving related
disputes through the judiciary or legislation are explained. Second, the paper describes the legislative background of the aforementioned two laws in Taiwan, including futile medical care, the denial of citizen autonomy with respect to serious injury and death by criminal law theory, the unwillingness of the judiciary to intervene, and disputes encountered at medical sites. Subsequently, we explain the primary content of these two laws, including patients’ rights to self-determination, the judicial procedures of medical institutions, and the operation of advance directives. Finally, this paper analyzes challenges in the Patient Right to Autonomy Act, including a lack of penalties, insufficiencies in medical institutions’ scope of the duty of disclosure, and the lack of a settlement mechanism for individuals who have not yet established advance directives.

Chih-hsiung CHEN is Associate Professor and Director of Institute of Technology Law, National Chiao Tung University, Taiwan. Prof. Chen earns his doctoral law degree from Washington University in Saint Louis, a master of laws degree and a B.A. in Philosophy from National Taiwan. Before joining academia, Prof. Chen was an attorney of law specializing in civil litigations. Prof. Chen is famous for research on the legal issues of innovative technology in healthcare, particularly in digital health. Prof. Chen served as Acting Chairperson of Research Ethics Committee for Human Subject Protection, National Chiao Tung University. He participated in many projects commissioned by Ministry of Health and Welfare, Taiwan, including topics in surrogacy, abortion, secondary use of data of the National Health Insurance system, food regulations, telemedicine, and regenerative medicine. He was invited to give talks in China, Japan, and the United States on patent linkage rules of generic drugs, end-of-life law, surrogacy, artificial intelligence application in healthcare, and legal education. He was visiting scholars at Harvard Law School and University of California, Berkeley, U.S.A.

Prof. Daniel Fu-chang TSAI

“The Ethical and Practical Challenge of the Patient Right to Autonomy Act in Taiwan”

This presentation will examine the ethical perspectives and practical challenges of the Patient Right to Autonomy Act which was passed in Jan 2016 and in effect since Jan 2019. The concepts of advanced care planning and advanced directive are introduced. The four principles of bioethics are adopted to justify the Act, and relevant legal regulations and professional guidelines in Western countries are compared. Then the characteristics of the Act and the challenges could encounter in its application are analyzed. The speaker will point out that only negative right in refusing life sustaining treatment is protected in this Act, not the positive right in demanding active euthanasia and assisted suicide. The
actualization of this Act is hoped to enhance the protection of patient autonomy and welfare as well as to facilitate communication on end-of-life decisions among patient, families and health care professionals.

**Fu-chang Tsai** is a professor in the Graduate Institute of Medical Education and Bioethics, and jointly appointed in the Department of Family Medicine, Graduate Institute of Clinical Medicine, and the Institute of Medical Device and Imaging at the National Taiwan University College of Medicine. He is also an attending physician in the Department of Medical Research and Chairman of the Research Ethics Committees at National Taiwan University Hospital, and the director of the Center for Biomedical Ethics at National Taiwan University. He was awarded honorary membership by the UNESCO Chair of Bioethics in 2015 and served as vice president of the International Association of Bioethics in 2016–17. He is currently the president of the Taiwan Association of Institutional Review Boards. He is also a member of the Merck Bioethics Advisory Panel since 2017. His research interests include cross-cultural bioethics, genetic ethics, transplantation ethics, clinical ethics and ethics consultation, research ethics and research integrity, and medical ethics education.

**Dr. Derrick Kit-sing AU**

Kit-sing AU received medical education at Brown University and specialist training in Hong Kong. He served in clinical service for two decades before taking up management positions in the Hospital Authority, including the position of Director of Quality & Safety. Dr. Au is Chairman of the HA Clinical Ethics Committee and member of the Ethics Committee of the Hong Kong Medical Council. He is also a writer on healthcare and humanities. A book newly published (生命倫理的四季大廈) looks at the journey of modern bioethics and how technologies create ethical challenges.

**Prof. Roger Yat-nork Chung**

Dr. Roger Chung is an Assistant Professor of the School of Public Health and Primary Care of the Chinese University of Hong Kong. A social and lifecourse epidemiologist by training, he conceptualizes the population health and healthcare issues using the lens of health equity and social justice in the areas of social determinants of health, poverty and deprivation, migrants’ health, patients with serious illness (including rare diseases and terminal illness) as well as aging-related issues of long-term/end-of-life care and multimorbidity to inform health services, system and policy.
Dr. Chung is a founding member of the Centre for Health Systems and Policy Research and the Research Centre for Migration and Mobility, an executive member of Centre for Quality of Life, and an Assistant Professor (by courtesy) at the Institute of Ageing. He is also an appointed member of the Public Health Global Challenge Steering Group of the Worldwide Universities Network, spearheading the direction of research and collaboration in public health for 23 international research universities in the world. Also, he is the inaugural US National Academy of Medicine International Health Policy Fellow ’19-21, studying the issues of health equity, and social determinants of healthy longevity.

Dr. Chung obtained the Bachelor of Arts (BA) degree in Public Health from Johns Hopkins University, Master of Health Science (MHS) from Johns Hopkins Bloomberg School of Public Health, and Doctor of Philosophy (PhD) degree from the School of Public Health of the University of Hong Kong.

Dr. Guo-bin CHENG
“Patient Decision Making Near End-of-Life in the Context of Medical Care in Mainland China” (中國內地生命晚期醫療情境下的病人決策)

此講題將探討目前中國內地生命晚期醫療情境下病人決策的影響因素。首先，講者將簡要介紹內地生命晚期醫療決策的幾種主要模式，然後，探討影響病人選擇的四種主要因素及其效應：1) 生命晚期醫療的專業規範；2) 相關的法律和倫理規範；3) 醫療保障體系和當前醫患關係狀況等社會影響因素；4) 病人的家庭和傳統家庭倫理秩序。最後，聚焦於醫學專業倫理如何回應在上述四個方面提出的挑戰，並就其中存在的核心難題與聽者展開討論。

程國斌（1977-），男，博士，副教授，東南大學人文學院醫學人文學系主任，江蘇省醫學倫理學會副會長，《中外醫學哲學》（香港）雜誌編委，美國密西根州立大學生命倫理中心兼職副教授。1999年獲得醫學學士，從事外科住院醫生工作兩年，2008年於東南大學獲哲學博士學位後留校任教，2015年-2016年美國密西根州立大學訪問學者。主要研究方向為生命倫理學、醫學倫理學、醫療社會史等。歷年來承擔過包括國家社科基金、教育部社科基金和江蘇省社科基金在內的科研課題多項，出版專著1部，參與教材編寫4項，發表論文20餘篇，主要包括基因技術倫理、臨床倫理、醫療社會史，和中美醫學倫理學比較研究等議題。
癌症晚期患者通常面臨身體、心理的巨大痛苦，部分患者亦面臨超越自身經濟能力的災難性醫療支出負擔。家庭照護與醫院照護作為緩解患者身心痛苦的主要途徑，在實現“優逝善終”這一目的時，各自功能有所側重，存在衝突及融合的空間。本研究基於南京市公立三甲醫院與社區一級醫院典型案例的比較，分析了家庭照護與醫院照護在以下三個方面的衝突：關於患者知情同意權利實踐的衝突、關於患者治療方案選擇與解釋實踐的衝突、關於患者個性化需求與標準化供給之間的衝突。以上三種衝突的表現程度及表現方式受患者家庭關係及結構、患者社會經濟地位、醫院的層級等多重因素影響。研究同時指出，推進死亡教育、建立受醫院、患者、家屬相關方信任的協商制度、完善相關法規程式是減少衝突、促進融合的有效手段。

張晶，女，1987年4月生，籍貫湖北。2009年本科畢業於中國人民大學社會學系，獲法學學士學位，2011年畢業於中國人民大學社會學系，獲法學碩士學位，2016年畢業於香港科技大學社會科學部，獲哲學博士學位。2017年至今於東南大學人文學院社會學系擔任講師，同時面向東南大學醫學院臨床專業本科生教授醫學社會學，其研究興趣為醫學社會學、政治社會學、法社會學，長期致力於中國醫患矛盾的社會治理、醫患關係、糾紛解決、公共輿論等議題的研究。先後在CHINA INFORMATION (SSCI)、《公共管理學報》、《中國青年研究》、《東大學報》發表論文多篇，文章被《中國社會科學文摘》《人大報刊複印資料》轉載。主持國家社科基金青年項目一項，獲江蘇省“雙創”博士計畫支持。擔任《公共管理學報》《公共行政評論》審稿人。
The insertion of feeding tubes in advanced dementia patients with feeding difficulties is commonly practiced in Hong Kong despite the lack of evidence to suggest its clinical benefit. Feeding tubes can cause harms including risk of gastrointestinal bleeding, increase hospital readmissions due to tube malfunctions and dislodgements, and increase use of restraints leading to poorer quality of life of patients. Guidelines from international societies have advocated for providing careful hand feeding as an alternative for adults with advanced dementia to support their dignity and quality of life.

Feeding tube decisions are influenced by factors including perceptions of benefit of family and clinicians, cultural attitudes and beliefs, concern for legal consequences, and practical challenges to providing careful hand feeding. In 2015, the Hong Kong Hospital Authority HA Guidelines on Life-Sustaining Treatment in the Terminally Ill noted that careful hand feeding is an ethically appropriate option in advanced dementia patients with feeding difficulties and provided guidance on the decision-making process. To promote comfort for end-of-life care patients with feeding difficulties, a Careful Hand Feeding Program was initiated at a geriatric step-down hospital in Hong Kong in 2017.

This paper will discuss the impact of this program on changes in the patterns of feeding mode decisions for advanced dementia patients. An ethical analysis through case discussions will explore the meaning and contradictions of promoting “choice” on feeding options in advanced dementia patients as well the challenges that remain for clinicians, family and carers.

Kwan-yuk YUEN is Clinical Assistant Professor at the Li Ka Shing Faculty of Medicine of the University of Hong Kong (HKU). Dr. Yuen is a specialist in geriatrics and palliative medicine. She earned her B.A. in Biochemical Sciences from Harvard University and her Doctor of Medicine from the University of Michigan Medical School. Her research is focused on serious illness communication and end-of-life care. She is a faculty trainer of VitalTalk, a non-profit organization that provides advanced training courses in serious illness communication in the United States and globally. She is a member of the Hong Kong Academy of Medicine Professionalism and Ethics Committee Task Force on Advance Directives. She was the Founding Editor of the CUHK Jockey Club Institute of Ageing Casebook on Ethical Decision-Making in End-of-Life Care of Older Adults.
Promoting advance care planning (ACP) has emerged as a global movement to empower people to contemplate and communicate end-of-life care preferences. Undeniably awareness towards ACP has been growing among the health professionals as well as the public over the years. Local studies consistently reported the positive attitudes and successful experiences in practice change. We acknowledge the theory-practice gaps in the promotion and implementation process. While ACP intends to reduce anxiety and sense of uncertainty towards future care in patients and their family members, discussion on death and end-of-life care issues is commonly regarded as offensive that induce unease. ACP highlights the role of health professionals in patient advocacy, but patients valued family harmony over self-determination. The ethical principle of respecting for patient autonomy underpinning the concept of ACP seems not of the utmost concern in the Chinese population. Rather, they generally considered that decision-making related to medical treatment should be made by medical doctors or family. Many patients trusted that they would be in good hands of health professionals or their family members, and likewise the latter two parties also believed that they would be able to make the appropriate decisions based on patients’ best interests in due course. ACP is often being seen as other clinical procedures with much concern over the “accuracy” in terms of right patient, right person to initiate the conversation, right timing, sound mind, right treatments to be discussed, and right documentation, and thereby become intimidating to both laypersons and health professionals. In recent years, much efforts have been devoted for strengthening intersectoral and multidisciplinary collaboration to fill the gaps through public awareness campaign, staff education and policy development. Yet, our reflection uncover that the paradigm shift has just begun.

Yue-lai CHAN is Associate Professor at the Nethersole School of Nursing, Faculty of Medicine, The Chinese University of Hong Kong. Her research interests focus on end-of-life care, gerontology as well as care ethics. She has conducted a number of projects on promoting advance care planning in the community through public talks and staff training and engaging older adults and people with advanced progressive diseases and their family members in the planning process in home-based, care home and hospital settings over the past ten years. Prof Chan currently serves as the council member of Hong Kong Association of Gerontology, Honorary Advisor of the Hong Kong Society for Rehabilitation, and member of the editorial board of Journal of Nursing Ethics and Asian Journal of Gerontology and Geriatrics.
Choice and Care—Realities from the Medical and Geriatric Wards

Majority of deaths in Hong Kong occur in public hospitals, substantially in medical and geriatric wards. Such settings predispose to the medicalization of death and pose difficulties to enable a good death individualised to the person’s preferences and cultural-psychosocial-spiritual circumstances.

Some practical challenges of delivering high quality end of life services in such settings relate to issues in: (a) identifying end of life (b) compassionate communication and advance care planning (c) personalizing care delivery (d) resolving ethical dilemmas and (e) care transitions complexities. This calls for wider organizational support, staff training, physical resources and care collaboration with other care providers.

This talk will share our geriatric team’s ongoing journey towards providing choice and care at the end of life by meeting some of these challenges. Our experiences include the use of risk scores to supplement clinical judgement for prognostication, tools for empowering staff communication, ward design to facilitate end of life care, inter-disciplinary teamwork, and medical social collaboration with old aged home and NGO providers from advance care planning to care delivery.

Poey-lyn Kng graduated from the University of Wales, College of Medicine. After undergraduate training in the UK, she started her career at Ruttonjee Hospital (RH), Hong Kong in 1992 and obtained specialist accreditations in Acute Internal, Rehabilitation and Geriatric Medicine. In 1996, she trained at Newcastle, UK in elderly care and obtained the Diploma in Geriatric Medicine, Royal College of Physician (RCP), London, followed by a Master in Health Administration, University of New South Wales in 2000. She is Fellow of the RCP, Edinburgh and London.

From 2012, she heads Ruttonjee Hospital’s elderly services with a comprehensive range of services extending from acute, convalescent to the community. Since 2015, as Service Director (Primary and Community healthcare) for Hong Kong East Cluster (HKEC), she overlooks Primary care clinics, Integrated Care and Discharge Support Services (ICDS), Community Nursing Services (CNS) and Community Geriatric Assessment Team (CGAT). She is cluster coordinator for The Community Dementia Support Scheme as well as for HKEC’s Patient Resource Centres. In 2016, she took up the chair for HA Patient Support Call Centre management committee.
She is currently the Chair of HAHO Geriatric Subcommittee and Council Member of Hong Kong Geriatrics Society and Hong Kong College of Physicians.

**Dr. Elsie HUI**

Dr Elsie HUI completed her medical training at Imperial College London and joined the Hospital Authority in 1992. She trained in Geriatric Medicine under Professor Jean Woo. Currently, Dr HUI is the Chief of Service and Deputy Chief Executive of Shatin Hospital. She is also the Service Director of Community Outreach Services and General Out-patient Clinics in New Territories East Cluster.

Dr HUI is a member of NT East Cluster’s senior management team and works closely with the Head Office of Hospital Authority in the planning of service models and funded programmes. She is an honorary lecturer at Chinese University and Polytechnic University and teaches healthcare professionals at undergraduate and postgraduate level. Her research interests include end of life care, frailty, nutrition and feeding in the elderly, and use of innovations to support the cognitively impaired.