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略談安樂死的正反論據

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安樂死應否合法化，目前爭論的焦點之一，仍然是「主動、自願的安樂死」，即因應病人的意願，由他人(通常是醫護人員)採取行動來終結病人的生命，以縮減其痛苦。本文將集中討論這種安樂死的正反論據，因為一方面，被動安樂死(不給予某些治療，讓病人自然死亡)已為大部份人所接受，包括很多強烈反對主動安樂死的人，已經毋須討論；而另一方面，由於篇幅所限，本文實不能涉及非自願安樂死這個更形複雜的問題。

贊成自願安樂死，主要是基於兩大理據。第一是尊重個人對自己生命的自主權，既然人應有權在不損他人的情況下選擇如何過活、如何安排自己的生命，則應該亦有同樣的權利選擇死亡。第二是基於病人本身利益的考慮，若病人身罹絕症，繼續生存只會延長無意義的痛苦，最終仍是一死，則維持其生命對他來說並不一定是件好事。至於支持主動安樂死，則是因為在接受安樂死的前提下，與其只是終止治療，讓病人飽受折磨而「自然死亡」，倒不如盡量縮短病人的死亡過程以減少不必要的痛苦。(余錦波, 93.12.24)

要注意的是，支持自願安樂死的兩大理據是必須連在一起考慮的。單基於自主原則並不能支持安樂死，因為在很多其他情況中，例如人因情緒低落而萌生死念，我們可以為了保障他的利益而合理地暫時剝奪其自主權；單基於病人的利益也是不可以的，因為究竟好死還是歹活更符合病人的利益，應該讓病人根據充分的資訊，在冷靜理智的情況下來作這個價值判斷，若病人有自決能力而仍由別人越俎代庖，那便是不尊重人的自主權了。

有些人不贊成安樂死，似乎正正是因為他們把上述的兩大理據分割了開來，獨立地加以評斷。他們擔心，若基於自主權或利益考慮而贊成安樂死，很容易會造成滑坡，漸漸變成容許「仁慈濫殺」，並不限於絕症病人才可接受安樂死，只要有人覺得自己生不如死，甚或他人判斷某人生命質素極差，便可以施行安樂死了。(Teichman, 頁68, 頁78-92; 羅秉祥, 93.12.3-93.12.5) 但這顯然是忽略了，自主權和病人本身的利益，都是在決定安樂死時必不可少的考慮。故此，至少在理論上，容許自願安樂死，並不會造成上述的滑坡。當然，人不是完全理性的，一旦打開了安樂死之門，在實際的社會效果上，會不會漸漸改變了人的心態，削弱了醫護人員救死扶傷的使命感，以至削弱了社會對病人的道義責任，因而造成上述的滑坡呢？這一點可以成為疑問。不過，任何社會政策都有可能因為人的不完美而被濫用、歪曲，我們又是否只因有這個可能而不去試驗推行一些在原則上是好的社會政策呢？若以安樂死合法化的荷蘭為鑑，至少到目前為止，尚未有証據顯示該國正向「仁慈濫殺」之路滑下去。(參考 Singer, 1994, 頁 150-156)

另一個對所謂「死亡權」的質疑，是指出凡權利皆有相對應的義務承擔者，故此，就主動安樂死而言，說我有死亡權，蘊涵了別人有應我的要求而殺死我的義務，這實在非常違反常情常理。(羅, 93.11.21; Teichman, 頁69) 這個論証，明顯是把死亡權視為一種積極權利，要求別人必須有所行動。然而，其實贊成安樂死的人，絕大部份只是把死亡權理解為一種消極權利，亦即一種自由，也就是說，他們所要求的，並不是社會或他人必須提供安樂死服務，而只是要求社會不要立法阻止醫生自願地提供安樂死服務而已；不自願的醫生，並不承擔任何殺人的義務。這樣的死亡權，我實在看不出有甚麼不合理之處。

也有人擔憂，容許安樂死會令醫護人員的角色混淆，既要救人，又要殺人，一則加重醫護人員的心理負擔，二則容易使其他病人憂慮醫務人員會了結自己的生命，從而削弱了醫者與病者的互信基礎。(鍾淑子, 95.9.4; Teichman, 頁86) 然而，若我們清楚地絕不容許不自願的安樂死，那又怎會引起病人憂慮呢？正如在一個法治嚴明的社會中，普通人是不會憂慮無辜陷獄的。至於角色混淆的問題，則可以有技術上的解決方法，就是另外成立一組專門負責安樂死的醫護人員，甚至另立一所專門醫院。

另外，有人反對安樂死，是認為很難確保病人的決定是理性和自主的，因為一旦安樂死成為一個選擇，病人很容易會受到家人或社會的無形壓力，覺得應該求死以解除家人和社會的負擔，其實並非真的想死。(鍾, 95.9.4; 羅, 93.12.6) 然而，這個論點只可証明絕症病人應受到特別的保護、照顧和輔導，讓他們能在冷靜理智的情況下決定自己的生死，並不表示我們必須一刀切地拒絕所有病人選擇安樂死的要求。

還有一個近來很多人提出來反對安樂死的論點，認為贊成安樂死是陷入了一種非黑即白的思維中，要麼就是任由病人飽受煎熬而死，要麼就是仁慈殺人，完全忽略了第三個可能的選擇 — 就是致力提供善終服務，一方面以先進的醫藥來減輕病人肉體上的痛楚，另一方面更著重提供心理照顧以及精神上和社會性的支持，使病人不會覺得活著是可憐悲慘或成為別人的負累，以致萌生死念，如此，我們根本就不需要容許安樂死了。(羅, 93.12.7; 鍾, 95.9.4; Teichman, 頁71-73) 我認為，這個論點並不能完全否定安樂死。要知道，有很多伴隨各種絕症而來的痛苦，是目前最先進的醫藥仍無法解決的，如不能進食、全身癱瘓、大小便失禁等等。這些狀況，在在都會使人感到尊嚴盡失，難以接受。設若在接受了完善的善終服務之後，仍有病者覺得歹活不如好死，那麼，若沒有安樂死的選擇，豈非等於變相強迫他多活幾十天他所不能接受的生命？這樣做又有甚麼意

義呢？其實，善終服務大可與安樂死並行不悖，一方面我們可以致力發展善終服務，盡量減少安樂死的需求，另一方面，對於善終服務也幫助不了的病人，我們便應尊重他對自己生命的自主權利，容許他有安樂死的選擇，這不是一個更理想的情況嗎？

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Some Ethical Issues in Clinical Research in the United States

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We are in a world where people are becoming more closely linked than ever before. Bioethical issues are universal, although the approach taken by various groups may be vastly different, depending on their tradition, culture, resources and priorities. No less controversial are the topics relating to bioethics in clinical research. Obviously there must be some minimal norm to which all who are engaged in this area must observe; hence the development of the Nuremburg Code and the Declaration of Helsinki, to name just two of the better known documents regarding ethical conduct in clinical research.

The practice of medicine and the execution of clinical research are evidently different in the East versus those in the West. Nonetheless, it may be useful to draw on the experience of others in anticipation of problems yet to show up.

Here I discuss several ethical issues in clinical research which have been under substantial scrutiny in the United States. These may also be pertinent in Chinese communities, although I am not sure how much they are being viewed as being important at this stage. These topics are: the right of inclusion, protection of the mentally incapable and scientific misconduct.

Right of Inclusion

Because of the widely publicized atrocities of the German and Japanese research machines involving human subjects some 50-60 years ago, participation in research in this country has been considered primarily from the perspective of risk-taking by the research subject. This is understandable, especially after the exposure of some egregious medical experiments in the U.S., including the Tuskegee studies. Today, clinical research involving human subjects must go through an independent "Institutional Review Board" which examines the study protocol to ensure proper protection of the subjects. In addition, the subjects must give "informed consent" after the investigator has detailed all the potential risks involved in the study.

Over the past decade, the attitude towards participation in research has gradually shifted. Instead of regarding this as a risk-taking exercise, many increasingly view participation as a right not to be denied because of potential benefits derived from the research. Two examples readily come to mind. In the early developmental phase of a drug, many of the potential hazards of the drug are unknown. Traditionally such "phase 1" studies exclude females of childbearing potential because of the risks of toxicity to fetus and the drug companies want to avoid expensive and time-consuming litigation. Now it is more common to have participation by women in these early drug trials because it is considered unacceptable to obtain data only from males which are potentially different from those obtained from females. The differences may be due to a variety of factors, including body composition, metabolism, hormonal environment, etc. In essence, data obtained from male subjects may not necessarily be applicable to females. If the study is to provide beneficial information for females, then females should not be denied participation.

An additional impetus to this more benign view of research participation as being a beneficial exercise came from the AIDS epidemic. Activists demanded access to experimental therapies which have not been approved for marketing. Inclusion in a clinical trial of a drug to be used for the treatment of HIV infection might make the difference between life and death for some subjects. Thus, to deny the right to inclusion may mean denying the right to life for these individuals. However, clinical trial protocols usually have strict criteria for enrollment and the right of the investigator to select subjects may be at odds with the right of the individual who wants to be included.

Clinical research should be looked at in totality. It offers both potential benefits and risks. A balance has to be struck in setting up selection criteria in clinical studies. This balance in selection may indeed be delicate. Ultimately participation has to be determined by both the subject and the investigator.

Protection of the Mentally Incapable Subject

The U.S. Code of Federal Regulations has explicitly required the protection of human subjects in clinical research (45 CFR 46). However, the regulations are not at all clear in the area of participation by the mentally impaired or incapable. "Informed consent" has been a cornerstone in the protection of human subjects. Yet this may be meaningless when the research subject is not able to give it. A subject may be unable to provide informed consent due to one or more reasons. The concept of informed consent hinges on an ability to understand the information given, and any condition that affects this ability is liable to make the consent not valid. Although children are not usually considered mentally incapable, consent by parents or legal guardians is needed, as children may give assent but not legal permission. Their participation in research should be able to pass the "minimal risk" and "commensurate experience" tests. In practice, consent of underage subjects is under the jurisdiction of laws of individual States.

The concern over participation of subjects with impaired cognitive ability has to do with their deficiency in comprehension of the study, due to either their disease state (organic or psychiatric) or treatment. At least the following issues may be encountered in the participation of such subjects: justification, subject representative, dependency and fluctuation of incapacity.

Justification. For a research involving patients unable to give informed consent, there must be some compelling reason for doing it, especially if there is no direct benefit to the patient. The information to be obtained must be vital to answering an important question relating to the patient's condition.

Representative for the subject. For research participation, the federal rules require consent by the subject or a legally authorized representative. The definition of a legally authorized representative is up to State law, but State laws rarely address this. Although an advance directive obtained from the subject before he/she becomes mentally incapable (living will or durable power of attorney) is often accepted for medical care, however, for research, it is important to have a representative who is able to understand the study and can make decisions based on an interpretation of whether the patient would participate if he/she were competent and in the patient's best interests.

Dependency. The power relationship between the investigator and the

subject is of substantial concern, especially if the research may be the only way for the subject to receive a treatment or any treatment at all in some cases. This issue is not unique to the mentally incapable, but these subjects are particularly vulnerable, especially if they are institutionalized.

Fluctuation of mental capacity. Research is not just an event, but a process. For some patients, the mental incapacity may be intermittent, whereas for others there will be no time when a state of full capacity can be expected. Fluctuations in mental state in either direction may also be related to drug intake. Clearly, withdrawal of consent must be allowed as in any other research. One should be conservative in research interventions and liberal in interpreting any communication that can possibly be conceived as unwilling.

Scientific Misconduct

While the practice of science is often regarded as self-correcting because correct findings will be corroborated and errors are usually irreproducible, this is not invariably the case. The acceptance of false findings by the scientific community may be costly in time and resources. In clinical research, this may even be dangerous to patients' health or lives. Since the 1970s, a number of widely publicized cases of scientific misconduct in the United States have made the public cynical of the process of science and suspicious of scientists. Unfortunately, these cases have all been in the biomedical research area.

In 1989, a Final Rule in the Federal Register defined scientific misconduct under the categories of fabrication, falsification and plagiarism (FFP). This was largely welcomed by the scientific community as a workable definition. In 1992, the National Academy of Science introduced two other items: questionable research practices and misconduct not unique to the pursuit of science. More recently, the release of a report on "Integrity and Misconduct in Research" by a commission sanctioned by the U.S. Congress has covered new grounds considered by many scientists as being too novel and controversial for implementation. Among these is "misrepresentation" in which even failure to cite a reference may be regarded as misconduct. At this time many continue to use the FFP definition.

Clinical scientists are not saints. However, there is no reason not to hold them to the highest ethical standards in pursuit of the passion of their lives, namely science itself. A definition of misconduct is important but is in fact an attempt to set limits on unethical behavior. Higher standards are attainable but difficult to define. For example, conflict of interest or even the appearance of conflict of interest should be avoided. In this modern world where financial opportunities are intimately linked to research in science and technology, there is a lot of food for thought on this item alone. Here I have not even addressed the ethical issues regarding the doctor-patient relationship when one's patient becomes one's own research subject.

Conclusion

> "Oh, East is East, West is West, and never the twain shall meet
> Till Earth and Sky stand presently at God's Great Judgment Seat."

Such was the dire prediction of Kipling. However, given the constant exchange of both ideas and personnel in a world shrinking daily under the pressures of high technology and cheaper travel, it would now be naive to believe that the East-West differences will remain for long. I reiterate here that bioethics is universal although approaches may vary from place to place. Significant issues in the United States of today may be important in Chinese communities of tomorrow. There is a proverb that it would be wise to start thinking of fixing the roof before it rains. Certainly there are as yet no satisfactory regulations in the U.S. for the issues discussed in this article, but work is being done towards that end. It would be easier for other countries to start thinking before such issues emerge as serious problems and emotions run high.

COMMENT 意　見

上海市部分人大代表提出議案要求國家允許在上海實施「安樂死立法」

中國協和醫科大學社科系 金大劼

在八屆全國人大二次、三次會議，都有代表聯名提案，要求結合國情，盡快進行「安樂死」立法。但均因「安樂死」立法涉及到法律、醫學、倫理學等各方面問題，需「認真研究」。建議衛生部會同有關部門對安樂死立法進行深入論証。全國性的立法條件尚未成熟，但可先在北京、上海等大城市立法，通過地方立法，總結經驗，再在全國推廣。

1996年3月，在八屆全國人大四次會議上，上海代表提出議案：要求國家允許上海市嘗試出「安樂死」地方性法規。所提立法草案規定安樂死實施範圍為患有肉體痛苦無法忍受的晚期不治之症的病人，主要為惡性腫瘤及紅斑狼瘤、艾滋病病人，而不包括在醫學上尚未統一死亡標準的腦死亡病人、植物人及先天性畸形嬰兒等。實施安樂死要根據本人意願，要有嚴密的法定執行程序和監督管理辦法。他們希望通過兩年的周密準備，在 1998 年完成立法工作。

上海代表還建議從今年起，在全市開展有關「安樂死」的宣傳：「安樂死」不是解決生死問題，而是解決「優死」問題，為了保障病人利益；不是提倡不治病人早死，而是為其中要求優死者提供法律保障和條件；「安樂死」不僅使醫務人員得到法律保障，而且規範其行為，使之不致產生不利於病人的違法行為；「安樂死」有利於病人、家屬和社會，有利於醫學科學、醫療事業的發展，有利於社會主義精神文明建設等等。

上海代表認為，實施安樂死要求社會全員文明程度提高、法制健全，這兩個條件上海已基本具備。一開始可以從單一病種，局部地做起，積累經驗，不斷完善。

MESSAGES 消　息

加拿大多倫多舉行「人類基因組國際會議」

由國際人類基因組組織 (HUGO) 舉辦的人類基因組國際會議是在人類基因組研究方面交流最新進展的大型年會。今年 1997 年 3 月6 - 8日在加拿大多倫多舉行，明年將在意大利舉行。 參加本次會議的各國代表有四千餘人。中國遺傳學家去的不多，僅有一、兩位來自湖南醫科大學。 但在國外學習、工作的大陸學者去的很多。他們的名字出現在論文摘要或版報上的很多，但發言的很少。

大會主要內容是交流人類基因組研究的進展，但有兩次會議涉及人類基因組研究的倫理學問題。一次是六日下午的研討會，題目是：「人類基因組研究中的倫理學」，會議由日本著名遺傳學家武部啟主持，發言的內容有：「基因組研究的倫理學含義」，「基因研究、人類多樣性和倫理學挑戰」，「人類基因組：人類的共同遺產」。另一次是七日下午的專題學術討論會，題目是：「從實驗室到病房，再從病房到實驗室」。會議由美國國立衛生研究院人類基因組研究社會、倫理和法律含義規劃主任Eric Meslin主持。會上發言的內容有：「基因組科學對醫學的積極影響和值得關注的領

域」，「隱私和保密」，「在具有非西方文化的發展中國家中的知情同意」。最後一個問題由邱仁宗教授發言。他在發言中指出：知情同意是總結納粹德國醫生非人道人體試驗基礎上提出的研究倫理學中的普遍原則，但這個原則在具有非西方文化的發展中國家中貫徹時，會遇到兩個方面的問題，一是信息理解上的困難：非西方文化的發展中國家往往擁有特殊的宇宙觀，例如熟悉陰陽五行語言的人難以理解基于原子分子語言的信息。二是表示同意上的困難：非西方文化的發展中國家中個人往往與他的家庭其他成員和社區成員處於比西方國家更為密切的關係中，因此這種同意往往不單是個人的同意，而同時也是家庭的同意，有時甚至需要社區的同意。邱教授將擔任國際人類基因組組織倫理委員會的委員。

瑞士日內瓦舉行「人人享有健康國際會議」

倫理學、公正與世界衛生組織重申人人享有健康（Health for All）國際會議由國際醫學科學組織理事會(CIOMS)主辦，於1997年3月12 - 14日在瑞士日內瓦舉行。會議邀請了各國著名的醫學家、公共衛生學家、哲學家、生命倫理學家、法學家參加。世界衛生組織總幹事中島(H. Nakajima)參加了這個會議。自從世界衛生組織提出「2000年人人享有健康」這個口號後，離開2000年只有三年的時間。世界上許多地區，許多人仍不能享有健康，在分配衛生資源上仍然很不平等。因此，世界衛生組織計劃重申這一口號，並且強調公正和人權。

香港生命倫理學會成立聚會

1997年5月30日香港生命倫理學會假座香港城市大學舉行第一屆週年大會，會長葉保強博士報告會務及提出來年計劃。會後聚餐，討論甚有興味。

香港生命倫理學會與香港哲學會於7月19日(星期六)上午在香港城市大學舉辦「複製人」研討會。講者包括香港中文大學的邵鵬柱博士、《信報》的李鈞陶博士，及台北國立中央大學的李瑞全教授。

台北舉行「應用倫理學區域會議」

台北中櫃國立中央大學文學院哲學研究所於1997年6月5日至6日舉辦「應用倫理學區域會議」。6月5日的「會前會」討論了複製人的科技及倫理問題。6月6日發表的論文共有十二篇，作者來自大陸、台灣、香港三地。大陸方面，邱仁宗與唐熱風兩位教授因出入境手續問題，未能及時出席。但論文仍引起與會者廣泛的興趣和討論。香港方面的論文，包括余錦波論應用倫理學方法、區結成論「不予復甦」指引、葉保強論香港關於商業倫理的研究。台灣方面的講者來自多個院校，包括銘傳管理學院鈕則誠、陽明大學陳宜民、政治大學彭文林、青輔會吳秀瑾、中央大學李瑞全、南華管理學院戚國雄、政治大學曾春海。

台北中央大學哲學研究所近年積極發展成為應用倫理學研究中心，提供專研應用倫理學的碩士課程，更成立應用倫理學研究室，出版《應用倫理研究通訊》，最近又舉辦「應用倫理學區域會議」，可算是華人社會中研究應用倫理學的一個重鎮。

預告…

	主題	負責編輯	截稿日期
第三期	醫療政策	區結成	七月十五日
第四期	複製人	邵鵬柱	十月十五日

美國最高法院裁定各州有權自行立法禁止安樂死

大約一年前美國最高法院決定研訊憲法保障之權利是否包括死亡的權利，最近（1997年6月）終於有了結果。美國大約有四十個州有法例禁止協助他人自殺，但死亡權利運動（Right-to-die Movement）的支持者卻挑戰州政府有製訂這種法例的權力。美國最高法院最近終於裁定，憲法保障的權利並不包括死亡的權利，紐約及華盛頓對安樂死的禁制被裁定有效。

鳴謝

承蒙香港大學醫學院院長周肇平教授慨捐港幣一千元贊助本通訊之出版，謹此鳴謝。

《徵求會員》

香港生命倫理學會在九六年底成立，目的是推廣本地及華人社區對生命倫理的關注。學會現公開招收會員，誠邀對生命倫理有興趣的朋友加入。有興趣者，請與學會秘書余錦波聯絡。

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