

End- of- Life Care

from an alternative point of view

Julia Tao

City University of Hong Kong

6 July 2017

Three thought-provoking titles

Quality of Care of Older Persons:

Study on Dying At Home

Professor E K Yeoh

Addressing **the Chasm between the Philosophical and Real Life** Perspectives to Ageing:

Making Bioethics Relevant to Society

Prof. Jean Woo

Care of Hong Kong Elders near End of Life:

Why paradigm won't shift?

Dr. Derrick Au

Paradigm Shift in End-of-Life Care

Shifting the paradigm's 3 core components:

- I. Public Discourse
- II. Philosophical Framework
- III. Prevailing Perspective

Paradigm Shift in End-of-Life Care

First : Shifting Prevailing Perspective

From the perspective of

“Dying with Dignity”

to

the perspective of

“Living with Dignity”

Underpinning moral assumptions:

life has value

living is a good in itself

Shifting Perspective

“Dying with Dignity” emphasizes:

- Protecting preferences about the dying process
- Maintaining pain-free status
- Promoting emotional well-being

Shifting the Prevailing Perspective

“Living with Dignity” emphasizes:

- (1) Maintaining a measure of **control** of bodily/daily functions to enhance capability and independence through affordable assistive technology

Maintaining a measure of bodily/functional control and dignity



A 預設程序 預先調校水溫及設定程序，用家只要安坐椅上即可啟動自動洗澡功能，過程中還提供語音提示步驟，令用家更安心。

B 一舉多得 淋浴裝置設於坐廁上，除了方便排水，亦能方便長者忽然便急之用。

C 防水實體鍵 由於長者未必懂得使用平板電腦或智能手機，所以在 Sit & Shower 的手柄位，特設防水實體鍵，並以不同顏色代表不同功能，令長者可在洗澡時自行操控部分程序。

科大生自動沖涼椅，為「老友記」沖涼挽回自尊

Maintaining a measure of bodily/functional control and dignity



城大生研自動變形輪椅協助輪椅人士上車

Maintaining a measure of bodily/functional control and dignity

長者科技展品



自動吸便機 韓國廠商研發的自動吸便機首次在港展出。將高科技吸管置於長期臥床的患病長者下體，連接特製尿片，就可以自動偵測及吸走排泄物，更可自動清潔長者身體。右圖為廠商用豆腐示範吸便機操作，當中所用的吸盤為女性用家而設，另有較細裝置適用於男性。

(郭慶輝攝)



「南瓜仔」笑哄長者

▼香港聖公會福利協會今年初購入日本的「南瓜仔」陪伴機械人，透過其發出的笑聲，與患有認知障礙的長者交流，讓其有精神寄託，以改善患者的粗魯行為。協會亦購入智能機械人，懂得打功夫、做體操等，逗長者歡笑。

(郭慶輝攝)



舒適「洗肚」椅



照鏡「睇」心情

Shifting the Prevailing Perspective

- (2) Expanding **connectivity** and **access** to “integrated,” “community-based” service teams for humanistic care and professional assistance in daily living: including emergency problem-solving, mobile healthcare, regular homecare and living environment enhancements

Expanding connectivity to integrated community-based support



工程及醫療義務工作協會

Association for Engineering and Medical Volunteer Services

地址：九龍石硤尾村44座平台207-212室

電話：27768569 傳真：27881194



Expanding connectivity to integrated community-based support



家居維修義工協會

家居維修遍各區
齊來共建樂安居

Repair Fairy

*A Volunteer
Association for Home
Repair*



Expanding connectivity to integrated community-based support



中電義工隊 CLP Volunteer Team

中電義工隊於1994年成立，現已增至11個工作小組，成員超過1,400人 (包括員工及其家屬、朋友)。團隊服務對象包括長者、殘疾人士、新移民和年輕人。除了「長者重鋪電線計劃」外，中電義工隊的服務範圍已擴展到提供免費的英語課程、培訓青年和長者義工領袖，及為社區的弱勢社群舉辦生態旅遊和其他活動。

Shifting the Prevailing Perspective

- (3) Sustaining “**integrity**” and individual self-understanding of the “**good life**”, to counteract the threats of fragmentation happening in one’s body, one’s environment, and one’s life

Sustaining integrity and self-individual understanding of the good life

Integrity involves the relation between a person's **sense of self** and **action**

Persons of integrity are loyal to the central principle and conviction to which their life is committed, and which gives **unity, wholeness** to their life

Losing one's integrity is in a sense losing one's moral identity (Bernard Williams, 1973)



Paradigm Shift in End-of-Life Care

Second : Shifting Philosophical Framework

II. Shifting the philosophical framework

from

“Intergenerational Justice”

to

“Intergenerational Reciprocity”

Justice as Negative Virtue

- “Justice”, whether distributive or procedural, is a negative virtue (Stuart Hampshire, 1989)
- It emphasizes “separateness” between individuals as strangers and protects “independence” and “rights” as the essential condition of human existence

Reciprocity as Positive Virtue

- “**Reciprocity**” is a positive virtue (Lawrence Becker, 1986)
- It is a recipient virtue of gratitude for the goodness or kindness she/he has received
- It implies a straight moral obligation on the part of the recipient to “**return good for good**”
- Reciprocity is not the same as “*quid pro quo*,” “fair exchange,” “repayment of debts” or a kind of “calculated investment return”

Reciprocity as a Central Chinese Moral Ideal

- Reciprocity does not have to be directed at any particular target person or the same person from whom kindness has been received
- “An earlier generation plants trees under whose shade later generations rest 前人栽樹，後人乘涼”
- “While you drink the water you must not forget those who dug the well for you 喝水不忘掘井人”

Reciprocity as a Central Chinese Moral Ideal

- The virtue of reciprocity, (跨代回饋、以德報德), enables us to see ourselves as part of a larger overlapping network of reciprocal relationships which join generations together in a shared world and continuous narrative
- It underscores our human relatedness and interdependency, shared fate and responsibility
- It promotes **trust and bonding** across generations - the moral glue of society

Paradigm Shift in End-of-Life Care

Third : Public Discourse

- III. Shifting the global “universalist” discourse on end-of-life care
to
locally situated “intersubjective” discourse, grounded in tradition, culture and society

2017年6月24日

謝俊仁

預設醫療指示在香港：發展與挑戰

信報 www.hkej.com



[放大圖片](#) / [顯示原圖](#)

鍾志強先生於2017年6月6日在《信報》發表〈預設醫療指示和環保殯葬普及化契機〉一文（下稱〈鍾文〉），指不少香港市民對預設醫療指示的關注，並提出具體意見，建議如何推動市民當身體健康時訂立預設醫療指示。對此議題，本文將作幾點討論。

預設醫療指示和環保殯葬普及化契機

鐘志強

免成親人不必要負擔

要指出的是，要訂立預設醫療指示的人，並不只是已經有嚴重疾病的市民，他們典型的特質，是年齡介於50至80歲，有照顧老人包括配偶、父母親和配偶父母親的經驗，健康程度可以是良好，預期餘下壽命超過10或20年，他們希望通過為自己訂立預設醫療指示，避免自己老年對親人做成不必要的負擔。

政府有責任為以上困難提供解決方案，就以上的困難，筆者認為政府可做的如下：（一）用諸如錄像等形式，就預設醫療指示內的醫療選項製作詳盡合適的解說，在網上公開讓市民參考。

上述建議政府可做的第一項，其功能有多方面。首先，它讓大部分市民毋須依賴醫生即可充分了解預設醫療指示內的醫療選項對自己選擇的意義，通過觀看能自行就預設醫療指示選項所須深思熟慮然後才作出決定；其次，通過這些錄像，市民的親人可更容易理解有關決定的意義，而和親人作出有意義的溝通；另一方面，醫生只要通過確認市民已觀看有關錄像，可以免除要通過面談確認市民理解自己作出決定的責任，有助大幅減低訂立預設醫療指示的成本和提升效率。

隨着市民的教育水平提高，政府甚至沒有理由強制健康市民要醫生為自己作證人，政府應能區分垂危的病人可能需要合適專業人士確認其行為能力，和健康市民預早訂立預設醫療指示等後多年才啟動的情況。一些大學調查已確認，高比例市民接受預設醫療指示和環保殯葬，只要政府能讓市民意願得以在其失去表達能力後仍然能清晰傳遞，社會能作出更適合時代需要的抉擇，或許，香港的「死亡質量指數」排名會因而追上全球競爭力排名。

Meaning of End-of-Life Decisions

- End-of-Life Care decisions are not merely about medical decisions or treatment choices, they cannot be decided on the basis of objective facts or subjective desires alone
- They involve moral questions and existential choices concerning “how to live?”, “what kind of existence to choose?”, “what is the good of life?””
- They are not the same choice as choosing moral principles or prioritizing which moral principle should trump in hypothetical situations
- End-of-life decisions in the real world carry very different moral weight, involving very different moral commitments at both the individual and the societal level

Global Bioethics or Global Dialogue ?

- There is no unanimity about the “good life” or the “good death”
- Moral discourse, moral narrative and moral commitments take different shape within particular cultures and traditions (H. Tristram Engelhardt, 2002)
- Instead of seeking to establish a comprehensive unitary global end-of-life bioethics
- We should create a continuing global dialogue based on respect for local differences, carried out through open, self-critical and rational discourse

Situating Universalist Discourse in Local Traditions

- Understanding the meaning and designing the rules and practice of end-of-life care is an **intersubjective process** involving a number of stakeholders and actors
- The participation of these actors and stakeholders will play out differently in varied, and sometimes conflicting, (sub) cultures where **intersubjective rules and meanings** are being proposed, negotiated and left open to renegotiation
- We should emphasize “**dialogical openness**”, in which prejudices are challenged and horizons broadened, and revisions made possible

Universality, Particularity and Philosophy

- Philosophy is often thought to be characterized by a search for the absolute and the universal, but such a view has been seriously challenged
- “Philosophical hermeneutics” (Gadamer 1960, Habermas 1982) explicitly rejects any **foundationalism** in the nature of human knowledge and Enlightenment **universalism** in ethics
- Hermeneutics emphasizes that we should reflect critically upon the meaning and significance of practices **within our own tradition and culture**, without any pretension to “universality”
- They see tradition as part of one’s very being; there is no escape from it into a realm of entirely universal maxims
- They argue that it is in moving forward from such “**particularity**” that the search for “**the good**”, for “**the universal**”, consists