

Ethical Issues and Dilemmas in Palliative and End-of-Life Care in the United States

美国纾缓治疗及临终关怀服务中的 伦理问题及困境

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Framing the Issue

The Western Perspective

从西方文化角度表述问题

1. **Decision-Making and Treatment 决策制定与治疗**

As more medical treatments emerge and life can often be prolonged, decisions must be made about what treatments should be given, what treatments should cease or be withheld, what treatments should continue when death is imminent.

更多的治疗方法出现，经常会延长患者的生存期，在死亡临近的时候，需要决定何种治疗应该被提供，何种治疗应该停止和拒绝给予，何种治疗应该继续。

Framing the Issue (cont)

表述问题（续）

2. Autonomy 自主权

The belief that individuals facing death, or their appointed surrogates, can have some control as to what care and treatment they receive is now widely accepted in the U.S. People can opt to forgo treatment and hasten death or choose heroic measures to sustain life. The decision belongs to the **individual**.

“濒死患者或其指定的代理人可以决定患者要接受何种照顾或治疗”的理念目前在美国已经被广泛接受。人们可以选择放弃治疗、加速死亡，或者选择无畏的方式来延长生命。决定的权利属于个人。

Framing the Issue (cont)

表述问题（续）

3. Truth-Telling 真相告知

An important consideration now challenging healthcare professionals is when and how to discuss the diagnosis and the expected trajectory of the illness and how to assist people to make decisions about treatment when it is futile and may increase pain and suffering.

医务人员的一个重要挑战是——什么时间、如何去讨论诊断和疾病预期发展进程，以及在治疗无效或可能带来疼痛和受苦时，怎样支持人们做出有关治疗的决定。

Basic Ethical Principles

基本的伦理原则

1. Beneficence: To do good; weighing the benefits of treatment and care against the risks, suffering and costs

有益：对患者有益；相对于可能的风险、痛苦和成本，衡量治疗或照顾可以带来的益处

2. Non-Maleficence: Do no harm; harm should not be disproportionate to benefits

不伤害：尽量不损害患者利益；即使损害无法避免，也要相对于给患者带来的利益保持合理比例

3. Respect for Autonomy: The rights of individuals to make decisions on their own behalf, including against treatment

尊重自主：尊重个体为自己做决定的权利，包括反对某些治疗

Basic Ethical Principles (cont)

基本的伦理原则（续）

4. Justice: Treating all patients fairly regardless of gender, race, religion, socio-economic status, sexual orientation, etc.

公平：无论任何性别、种族、宗教、社会经济地位、性别取向等，公平对待所有患者。

5. Truthfulness: Honesty about the diagnosis and treatment options, clear and understandable exchange of information

诚实：诚实对待诊断及治疗选择，提供清晰和易于理解的讯息

6. Privacy and Confidentiality: The duty to respect privacy of information – HIPPA law.

隐私及保密：有责任尊重及保护私密信息——HIPPA法案（Health Insurance Portability & Accountability Act, 健康保险携带和责任法案）

Self Determination

Based on the Principle of Autonomy

自决——基于自主原则

- Autonomous persons can make informed decisions on their own behalf; including designating a surrogate decision maker
有自主权的患者可以代表自己做出知情决定，包括指定一个决策代理人
- The individual in Western Society is central 西方社会以个体为中心
- When patients lack capacity – the surrogate decision maker is whoever has been determined by the patient beforehand or is legally determined if surrogate is not designated (a spouse, child or close relative may be legally empowered offering substituted judgement)
当患者缺乏能力—代理决策人可以是患者事先指定的任何人，如果患者没有事先指定，也可以依法确认（配偶、子女或近亲都可能被依法授权代替患者做决定）
- The surrogate may be guided by advance directives (living wills, health care powers of attorney, wishes expressed to family or doctors). 代理人可能根据预先指示处理（生前预嘱，委托人的医疗照顾权力，向家人或医生表达的愿望）

Self Determination

Ethical Dilemmas

自决——伦理困境

- Advance Directives do not always reflect clearly what the patient would want **at any given time** in the progression of the illness
预先指示不能总是清晰地反应在疾病进展过程中任何特定时间患者想要的
- Surrogates may not be guided by patient's best interests
代理人也可能没有以患者的最大利益为导向
- Should the autonomous decisions of a patient be overruled? Under what conditions? 患者的自主决定是否可以被驳回？在何种情形下？
- If decision-making capacity is in question: capacity vs. competence
如果要考虑决策能力：行为能力 vs. 胜任能力

Self Determination

Ethical Dilemmas (cont)

自决——伦理困境（续）

- In the U.S., the interests and needs of family and community in decision making is not the primary consideration unless it is indicated by the patient
在美国，在制订决策的过程中，除非患者指出，否则，家庭和社区的利益及需要是不被优先考虑的
- Scarcity of resources/Social Policy Issues: who should pay for expensive and scarce resources? Or if it denies access to others, who could utilize it better (e.g. organ donation)
资源/社会政策缺乏的问题：谁应该为昂贵或稀有的资源付费？或者如果它否认其他人有权使用，谁可以更好地利用（例如器官捐赠）？
- How does this affect the individual? doctor or healthcare provider?
Obligated to patient or society?
这给个体带来怎样的影响？医生或者医疗照顾提供者？对患者或社会的义务？

Self Determination

Ethical Dilemmas (cont)

自决——伦理困境（续）

- Futile Care: The doctor may believe the care cannot be of help and may increase patient suffering; how is decision made when continued treatment provides little or no benefit to the patient.
无效照顾：医生会认为照顾没有帮助、增加患者的痛苦；当治疗对患者只有很小的益处或根本无益时，该如何做出决定
- Coercion: no undue force or pressure to influence a patient's decision about treatment 强迫：没有不适当的压力影响患者做出关于医疗的决定
- Keeping the secret: Knowing the diagnosis when the patient does not want to know 保守秘密：了解诊断结果，但患者却不想知道
- Conflicts between patient and family as to what the patient is and is not told 关于患者什么被告知/没有被告知，而在患者和家人之间发生的冲突

Current Policy Issues in the U.S

目前美国的政策

- Limited Palliative Care Availability and Accessibility
有限的纾缓治疗可获得性和可及性
- Physician-aided death: Controversial (available in OR)
医生协助死亡：有争议的（在手术室中存在）
- Persistent Vegetative State: Should life sustaining treatments be continued in this situation? What do we know or are learning about brain activity?
持久性的植物人状态：这种状态下，维持生命治疗是否应该继续？关于大脑活动，我们已经知道和需要了解什么？
- Denial of treatment when it is considered futile: who decides, who pays?
当治疗被认为无效时，对治疗的否定：谁决定？谁支付？

Ethical Decision Making Process

伦理决策制定过程

1. Clarify the relevant medical, psychosocial, cultural and spiritual facts of the case and the values of the patients, family and community.
澄清与个案相关的医疗、社会心理、文化及灵性因素，以及患者、家庭与社区的价值观
2. Identify and describe the ethical issues and areas of controversy (*ex. Decisional capacity; refusal of care; informed consent or coercion, etc.*)
确认和描述伦理问题及存在争议之处（例如，决定能力；拒绝照顾；知情同意或者受到逼迫，等等）
3. Identify the relevant ethical concept (*beneficence, autonomy, justice*)
确认相关的伦理概念（有益，自主，公正）
4. Formulate reasonable options (*What are the choices for the patient, doctor and family?*) 阐述合理的选择（对于患者、医生和家人来说有哪些选择）
5. Facilitate discussion among healthcare professionals, patients and family.
促进医疗照顾团队、患者和家人之间的讨论
6. Decide how to proceed and what aspect takes priority over others.
决定如何着手，哪些方面是优先于其它的

Four Box Method 四箱法

Medical Indications

The Principles of Beneficence and Nonmaleficence

医疗指示

“有益”和“不伤害”的原则

Patient Preferences

The Principle of Respect for Autonomy

患者优先权

“尊重自主”的原则

QUALITY OF LIFE

The Principles of Beneficence, Nonmaleficence, and Respect for Autonomy

生活质量

“有益”和“不伤害”原则，
“尊重自主”

CONTEXTUAL FEATURES

The Principles of Justice and Fairness

情境特征

“公正”和“公平”原则

Social Work Role in Ethical Issues

伦理问题中社工的角色

- Assessing the psychosocial situation and bringing this information to the healthcare team; collaborating in plans of care and team decisions.
评估社会心理情境，并将所得信息带给医疗团队；合作制定照顾计划和团队决议
- Speaking with the patient and the family to understand values, wishes, and perspectives and to mediate when there are conflicts
与患者和家属谈话，了解价值观、愿望和想法，在有冲突时进行调停
- Advocating for the patient's right to choose a self-determined death even if it conflicts with a family's wish and needs – acting as a bridge.
倡导患者自主决定死亡的权利，即使与家人的愿望和需要有冲突—扮演沟通桥梁的角色
- Educating the team about cultural perspectives
为团队提供有关文化视角的培训

Social Work Role in Ethical Issues (cont)

伦理问题中社工的角色（续）

- Understanding if patient has informed consent or is coerced into a decision
了解患者是否知情同意，或者是被迫做出决定
- Helping patient/family understand treatment decisions and alternatives
帮助患者/家庭了解治疗决定和其它选择
- Helping patient and family with the decision-making process: family dynamics and family functioning – mediation
在决策过程中为患者和家人提供帮助：家庭动力和家庭功能—调解

Social Work Role in Ethical Issues (cont)

伦理问题中社工的角色（续）

- Helping patients gain supportive care: physical, emotional and health-wise
帮助患者得到支持性照顾：生理、情绪和明智的健康照顾
- Advocating for patient's wishes with family and with team (*ex: patients who want treatments that the doctor or team feel is inappropriate or futile*)
向家人及团队提议患者的愿望（例如：患者希望接受医生或团队觉得不合适或无效的治疗）
- Helping patient identify and decide surrogate decision maker
帮助患者确认和指定决策代理人
- Provide supportive counseling for patient and family
为患者和家属提供支持性辅导

Ethical Issues in Hospice Care

宁养服务中的伦理问题

Access to hospice care 宁养服务的可及性

- How referrals are made 如何转介
- Payment and financial issues 支付和经济问题
- The 6 month rule under Medicare Hospice Benefit
联邦医疗保险计划支付条件下的6个月生存期原则

Obligation to tell patient full information about their illness and prognosis

有义务告知患者有关其疾病与预后的充分信息

- Patients must sign an informed consent before admission
患者在入院前需签署知情同意书

Ethical Issues in Hospice Care (cont)

宁养服务中的伦理问题（续）

- **Quality of Care (For-Profit concerns)**
照顾质量（考量利益）
- **Withholding of fluids and nutrition**
撤掉人工营养与水分支持
- **Use of morphine and respiratory depression**
使用吗啡及呼吸抑制
- **Withdrawal of aggressive curative care**
停止积极/治愈性治疗
- **Physician assisted deaths and request for euthanasia**
医生协助死亡和“安乐死”的请求

YOUR EXPERIENCE IN CHINA? 你们在中国的经验？

What ethical issues and dilemmas do you and your team face?
你和你的团队面临哪些伦理问题及困境？

How does our interpretation of the basic ethical principles differ?
我们对于基本伦理原则的解释怎样不同？



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