

OVERVIEW OF PALLIATIVE AND END-OF-LIFE CARE IN THE UNITED STATES

美国纾缓治疗及临终关怀概览

THE VARIOUS MODES OF DELIVERY OF CARE, THE INTERDISCIPLINARY TEAM AND THE SW ROLE

多元化的服务提供模式，跨学科团队
以及社会工作的角色

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SILVER SCHOOL
OF SOCIAL WORK

Introductions 简介

- Our experience and background
我们的经验与背景
- Here to *teach* and to *learn*
是教学，同时也是学习
- We are offering **our** perspective and approach, not the only way to do things.
提供我们的观点与方法，但并不是唯一的方法

Definition of Palliative Care

纾缓治疗的定义

“Palliative Care is an approach that improves quality of life for patients and their families facing the problems associated with life-limiting illness. This is accomplished through the prevention and relief of suffering by means of early identification and comprehensive assessment and treatment of pain and other physical, psychosocial, and spiritual problems.”

“纾缓治疗是一种改善面临威胁生命疾病的患者及其亲人的生活质量的方法。主要通过早期识别、评估和治疗疼痛及其它生理、社会、心理和灵性问题，预防和缓解他们的痛苦。”

World Health Organization, 2015

Elements of Palliative Care

纾缓治疗的要素

- Palliative Care can operate alongside therapies that aim to prolong life and treat the illness aggressively such as chemotherapy, radiation therapy and others
纾缓治疗可以与其它积极延长生命和根治疾病的治疗如化疗、放疗等同步进行
- It is appropriate for people of any age 适用于任何年的人群
- It can be initiated at **any** stage of the illness – from early diagnosis until death 可以在疾病进程的任何阶段开始 – 从早期诊断直到死亡
- It is a **patient-centered** approach to care. 是以病人为中心的照顾模式
- Relief from pain and other distressing symptoms
缓解疼痛及其它痛苦症状

Elements of Palliative Care (cont)

纾缓治疗的要素（续）

- Integrates psychological and spiritual aspects of patient care
融入对患者心理及灵性层面的照顾
- Offers a support system to help patients and families cope
为患者及其家属提供支持系统以协助其应对
- Uses a team approach to address patient/family needs
运用团队的方法来解决患者/家属的需要
- Enhances quality of life
提升生活质量

World Health Organization, 2015

Definition of Hospice Care

宁养服务的定义

“Hospice provides support and care for persons in the last phases of an incurable disease so that they may live as fully and as comfortably as possible. Hospice recognizes that the dying process is a part of the normal process of living and focuses on enhancing the quality of remaining life. Hospice affirms life and neither hastens nor postpones death.”

宁养服务为那些患有不可治愈疾病的末期病人提供支持 with 照顾，帮助他们尽可能舒适和最大程度地活到最后。宁养服务将死亡过程视为生命的正常部分，并将重点放在提高患者生命最后阶段的生活质量。宁养服务重视生命，不加速或延迟死亡。

Elements of Hospice Care

宁养服务的要素

- Focus on caring *not* curing 重在照顾而非治愈
- Usually for patients with life expectancy of 6 months or less.
通常服务对象的预期生存时间为6个月或以下
- Team-oriented approach to alleviate pain and to provide symptom management, emotional and spiritual support
团队导向的方法缓解疼痛，提供症状控制及情绪、精神支持
- Support provided to families and caregivers 为家人及照顾者提供支持
- Bereavement and grief counseling services available 提供哀伤辅导与支持
- Care provided in the home, freestanding hospice centers, hospitals, nursing homes or other long-term care facilities 服务地点可以是患者家里、独立的宁养中心、医院、护理院或其它长期照顾机构
- Covered under Medicare, Medicaid, private insurance plans and managed care organizations 被联邦医疗保险计划、医疗补助计划、私人医疗保险及其它管理式医疗机构所覆盖

The Interdisciplinary Team

跨学科团队

- Most social workers in palliative and end of life care practice work in a team environment with doctors, nurses and other health care professionals 大部分从事纾缓治疗及临终关怀的社会工作者都是与医生、护士及其他医疗专业人员在一个团队内合作
- Teams need structures and organization in order to function effectively 团队需要一定的组织架构及管理才更有效地运作
- Teams have goals and a mission 团队有特定的目标及宗旨
- Teams have a culture – a way in which problems are presented and dealt with, conflicts handled, power is distributed: *team dynamics* 团队文化 – 提出和解决问题、处理冲突以及权力分配的方式: *团队动力*
- Team members have different roles, which sometimes overlap, and different areas of expertise 团队成员有不同的角色及不同领域的专长, 有时会重叠

Advantages of an Interdisciplinary Team

跨学科团队的优势

Patients/Family 患者/家属

- ❑ Integrates Care 整合的照顾
- ❑ Brings a wider range of services to the patient
为患者带来范围更广泛的服务
- ❑ Facilitates more expert treatment planning 促成更专业的治疗方案

Team Members 团队成员

- ❑ Distributes the responsibilities of care; decreases burden, including emotional, for individual practitioners 分担照顾责任，减少每一个团队成员的压力，包括情绪上的压力
- ❑ Maximizes resources 资源最大化
- ❑ Promotes innovation and quality care 推动创新及提升照顾质量
- ❑ More efficient 更有效率

Social Work Role on the Interdisciplinary Team

社工在跨学科团队中的角色

- Work collaboratively within the team 在团队中与其他成员协同工作
- Advocate for patient's needs and rights 倡导维护患者的需求及权益
- Bring psychosocial information into team discussions (e.g.: complex family and social situations, financial issues that influence reception to care, barriers to compliance) 提供社会心理资讯供团队讨论（例如：影响患者接受照顾或给依从性带来障碍的复杂的家庭及社会环境、经济问题等）
- Help team to operate more efficiently and effectively 帮助团队更有成效地运作
- Help team to understand social work role and competencies and the competencies of other team members 帮助团队理解社会工作和其他团队成员的角色与能力
- Be part of treatment decision and plans of care discussions 参与讨论治疗方案及照顾计划

Social Work Role on the Interdisciplinary Team

社工在跨学科团队中的角色（续）

- Take a role in leadership – doesn't only have to be the MD!
扮演领导者的角色 – 团队领导者不一定非要是医生
- Facilitate team collaboration
促进团队协作
- Help team members face patient's death and deal with loss
帮助团队成员面对患者的死亡及应对失落
- Knowledge of patient's cultural perspectives
了解患者独特的文化视角
- Participate in discussions of ethical decision-making
参与和决策制定相关的伦理问题的讨论

How Social Work Can Help Your Team

社工怎样帮助你们的团队？

Example from the Medical Literature: 来自医疗文献的举例

Avoiding Iatrogenic Harm to Patient and Family While Discussing Goals of Care Near the End of Life 临终阶段讨论照顾目标时避免对患者及家属的医源性伤害

- Authors 作者: Weiner and Roth
- Journal of Palliative Medicine 姑息医学期刊 (2006)

This article discusses **five** unintended physician/team behaviors that interfere with successful “goals of care” discussions with patients/families and could cause harm

文章指出医疗团队常见的五种可能会妨碍与患者及家人沟通“照顾目标”并造成伤害的非故意行为

****Social work could help teams avoid all them given our training and skill set****

****社工所接受的专业训练，可能帮助团队避免这些行为****

Five unintended physician/team behaviors that interfere with successful “goals of care” discussions with patients/families and could cause harm

医疗团队常见的五种可能会妨碍与患者及家人沟通“照顾目标”并造成伤害的非故意行为

- **Initiate discussion without assessing for patient/family readiness**
在讨论照顾计划前，没有评估患者及家人是否准备好了讨论死亡与濒死
- Unintentionally link relief of suffering with a demand that pt/family accept limited life span
无意识地将要求患者及家人接受濒死与缓解痛苦联系起来
- **Team believes pt/family is “in denial” when it is normative grief**
将患者及家人正常的哀伤与冲突错误诊断为对医疗现实的“否认”
- Team engages in distracting and destructive debates with patient/family about medical reality of impending death
与患者及家人陷入辩论，企图说服他们接受濒死事实
- Team present value-laden medical decisions in a binary manner
用二元的提问方式，讨论受主观价值影响的医疗决定

Initiate discussion without assessing for patient/family readiness

在讨论照顾计划前，没有评估患者及家人是否准备好了讨论死亡与濒死

- Social workers routinely assess patient/family knowledge of the illness, understanding of prognosis, wishes, hopes and world view

社工常规地评估患者/家庭对于疾病的认识，对预后的理解，心愿，希望和世界观等

- Social workers routinely assess the patient and family's past and present functioning; prior experience with illness; concurrent stressors; spiritual beliefs and their explanatory models of illness and health

社工常规地评估患者和家庭过去与现在的功能；先前的疾病经验；并存压力源；精神信念以及对于疾病和健康的解释模式

Team believes pt/family is “**in denial**” when it is normative grief
将患者及家人正常的哀伤与冲突错误诊断为对医疗现实的“否认”

- “I can’t believe I have cancer” or “My mother can’t be dying” is a normal reaction to bad news
“我不能相信自己得了癌症”或“我妈妈不可能快死了”是对坏消息的正常反应
- Social workers help patients and families process their grief – this cannot be rushed
社工帮助患者及家人处理他们的哀伤 —— 这是急不来的
- When patients and families are in crisis, social workers partialize the problem and lend their problem-solving abilities to the patient and family – ego-supportive counseling
当患者和家人处于危机时，社工分担问题，并将他们解决问题的能力传递给患者和家人 —— 自我支持辅导

THE SOCIAL WORK ROLE

社会工作角色

What Do We Do? 我们做什么？

- Bio-psychosocial-spiritual assessments
生理-社会-心理-灵性评估
- Participate in team and family discussions around treatment decisions and shifts in goals of care
参加团队及家庭关于治疗决策以及转变照顾目标的讨论
- Facilitate discussions of advance care planning
促进对于预立照顾计划的讨论
- Counseling and psychosocial support for patients and families (In the U.S. there is a high value placed on discussion of feelings)
为患者及其家属提供辅导及社会心理支持（在美国很看重对于情绪的讨论）

What Do We Do? (cont)

我们做什么？（续）

- Community Resources 社区资源
- Helping patients and family optimize comfort and quality of life (legacy work, life review and other creative interventions)
帮助患者及其家属最大化地提高舒适度及生活质量（留下遗物，生命回顾及其它创造性的介入）
- Helping patients feel connected and not abandoned
帮助患者感受到与他人的连接，并没有被抛弃
- Advocacy: Helping patient's verbalize their wishes and participate in planning for their care
倡导：帮助患者表述自己的愿望，参与制订自己的照顾计划
- Psychosocial education 社会心理教育

What Do We Do? (cont)

我们做什么？（续）

- Prepare and support patient, family, and children to face death and dying process and for loss, grief and bereavement
支持患者、家人及儿童做好准备面对死亡、死亡过程、失落、丧亲及哀伤
- Research 研究
- Leadership Activities 领导力活动

PELC SW competencies

PELC社工的能力（1）

- Assessment: bio-psycho-social-spiritual
评估：生理-心理-社会-灵性
- Engagement: therapeutic alliance; establishing trust
参与：联合治疗；建立信任
- Interventions: 介入
 - ▣ Ego-supportive counseling: individuals, couples, families, groups
自我支持辅导：个人，夫妻，家庭，团体
 - ▣ Cognitive Behavioral techniques
认知行为技巧
 - ▣ Family systems work; family meetings
家庭系统工作；家庭会议
 - ▣ Pain and symptom management
疼痛及症状控制

PELC SW competencies

PELC社工的能力（2）

- Interventions: 介入
 - Bereavement counseling
哀伤辅导
 - Goals of care discussions
照顾目标的讨论
 - Assess and help explore/explicate/resolve ethical dilemmas
评估并协助探索/解释/解决伦理困境
 - Advocacy and entitlements
倡导和充权
 - Team support and team maintenance
团队支持与维系
 - Evidence-based interventions
循证干预

Education for the PELC Social Worker

纾缓治疗社会工作者的教育

- Most social workers in the US have master's degrees but some are trained only at the bachelor's level.
美国大部分社会工作者具有硕士学位，但也有一些只是具有本科学位
- In the field of palliative and end-of-life-care, a master's degree or a doctorate degree is typical
在纾缓治疗及临终关怀领域，具有硕士或博士学位是很典型的
- Lack of training in palliative and end-of-life care in MSW education, most learn on the job.
社会工作硕士教育中缺少关于纾缓治疗及临终关怀知识的培训，大部分是在工作中学习的
- Post-master's certificate programs in social work and palliative care are available and growing
开设有纾缓治疗社会工作硕士资格证书课程，而且不断增加
- Some increase in MSW coursework related to palliative and end-of-life care due to increased interest
基于不断增长的兴趣，社工硕士学位课程中有关纾缓治疗和临终关怀的内容有所增加

Zelda Foster Studies Program

Zelda Foster 项目

Mission 宗旨

To develop and mentor the next generation of palliative and end-of-life care social work leaders in clinical practice, administration, research, policy, and education

培育和引导在纾缓治疗及临终关怀
临床实务、管理、研究、政策及教育领域的
下一代社会工作领袖

Three Program Components

三个项目内容

MSW Fellows

- ***Focused learning and career-building for students/beginning social workers***
- Enhanced field placements
- Educational and case seminars
- Mentorship and career guidance
- Funding for conferences and professional development

Post-Masters Certificate

- ***Enhancement of PELC competencies (knowledge, skills, and attitudes) for social workers early in their career***
- One-year intensive educational program
- Courses promote integration of theory and practice
- Capacity-building through development of over 150 experts in palliative social work

Leadership Fellows

- ***Advanced professional development and mentorship for mid-career emerging leaders***
- Seminars in advanced topics in PELC practice, research, knowledge dissemination and leadership
- One year of intensive mentorship
- Capstone projects

Three Program Components

三个项目内容

MSW

- **着重学生/新入职社工的学习及职业建设**
- 加强临床实习
- 培训课程或案例讨论会
- 导师及职业规划
- 资助专业研讨会及专业发展

研究生证书课程

- **提升社工在职业早期有关PELC的能力
(知识, 技巧及态度)**
- 一年密集型培训项目
- 促进理论与实践融合的课程
- 通过发展超过150个在PELC领域的专家, 推动能力建设

领导力

- **为事业中期形成的社工领袖提供进阶的专业发展及指导**
- 有关PELC实务、研究、知识传播及领导能力等进阶题目的研讨会
- 一年的密集型指导
- “顶石” (Capstone) 项目

Current Problems for Social Workers

目前社会工作者面临的问题

- Professional Isolation: often the only palliative care or hospice social worker
专业孤立：通常只是纾缓治疗或临终关怀社会工作者
- Lack of clinical supervision by a social worker
缺乏来自资深社工的临床督导
- Lack of social work leadership (decline in hospital social work departments)
缺乏社会工作领袖（医院社会工作部门的衰退）
- Lack of role clarity as case managers and others shared historic social work functions
承担个案管理者或其它传统社会工作职能，缺乏角色明晰度

WHAT ABOUT SOCIAL WORKERS IN CHINA? 中国的社工又如何？

How do you define your role?
如何定义你们的角色？

What is similar and different?
相似点及不同点？

What can we learn from each other?
我们彼此之间可以学习什么？



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