

OVERVIEW OF PALLIATIVE AND END-OF-LIFE CARE IN U.S  
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

Susan Gerbino, PhD, LCSW  
Terry Altilio, LCSW

NYU Silver School of Social Work  
Zelda Foster Studies Program in Palliative and End-of-Life Care

## 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 United States perspective and approach, not the only way to do things.  
提供美国的观点与方法，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  
世界卫生组织，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 适用于任何年龄的人群
- 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
- Advocates relief from pain and other distressing symptoms  
缓解疼痛及其它痛苦症状

World Health Organization, 2015

## Elements of Palliative Care 纾缓治疗的要素

- 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与照顾，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。

National Hospice and Palliative Care Organization, 2015

## Elements of Hospice Care 宁养服务的要素

- 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 symptoms.  
团队导向的方法缓解疼痛, 提供症状控制及情绪、精神支持
- Provide emotional and spiritual support 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 with some variation based on setting and age 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 practicing in palliative and end-of-life care work in a team environment with doctors, nurses, chaplains 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、牧灵人员及其他医疗专业人员在一个团队内合作
- Teams need structure 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 and varying comfort working in a team  
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

- Integrated 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

- Distribute the responsibilities of care which may mediate impact, 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
- Maximize resources 资源最大化
- Promote innovation and quality care 推动创新及提升照顾质量
- May be more efficient 更有效率

## THE SOCIAL WORK ROLE ON THE INTERDISCIPLINARY TEAM 跨学科团队中社会工作的角色

## Social Work Role 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
- Shared advocacy 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, cultural aspects that influence receptivity and access to care, factors impacting adherence)  
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)
- Contribute to team learning, efficiency and effectiveness  
帮助团队更有效地运作
- Demonstrate and articulate the social work role and competencies as they relate to 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
- Actively participate in treatment decisions and care planning  
参与讨论治疗方案及照顾计划

## Social Work Role 社工在跨学科团队中的角色

- Take a role in leadership – doesn't only have to be the MD!  
扮演领导者的角色 – 团队领导者不一定是非要是医生
- 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

## 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, evolving illness and shifting goals of care  
参加团队及家庭关于治疗决策、疾病进展及转变照顾目标的讨论
- Facilitate range of discussions which inform advance care planning  
促进对于预立照顾计划的讨论
- Counseling and psychosocial support for patients and families adapting to culture and coping styles (In the U.S. there is a high value placed on discussion of feelings)  
为患者及其家属提供与其文化及应对模式相适应的辅导及社会心理支持（在美国很看重对于情绪的讨论）

## What Else Do We Do? 我们还可以做什么?

- Research and provide community resources 研究和提供社区资源
- Intervene with patients and family to 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（留下遗赠，生命回顾及其它创造性的介入）
- Enhance patients connections to minimize feelings of abandonment 帮助患者感受到与他人的连接，减低被抛弃感
- Advocacy focused on identifying patient and family values, wishes and goals to guide their plans of care 倡导：侧重识别对照顾计划产生影响的患者及其家庭的价值观、愿望与目标
- Psychosocial education focused on multidimensional aspects of illness, loss and adaptation  
社会心理教育：侧重疾病、丧亲和心理适应的多元维度

## What Else Do We Do? 我们还可以做什么?

- Assessment, anticipatory guidance and focused interventions to support patient, family, and children to participate in their shared and individual responses to dying process and death  
通过评估、先期辅导和针对性干预，协助患者、家庭及儿童处理其对死亡和临终的共有或个别反应
- Interventions which focus on loss, current and future aspects of grief and bereavement  
侧重于失落，哀伤与丧亲的当前与未来方面的干预
- Research 研究
- Leadership Activities 领导力活动

## PELC SW Interventions PELC社工介入

- 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 Interventions PELC社工介入

- Interventions: **介入**
  - Bereavement counseling  
**哀伤辅导**
  - Goals of care discussions  
**照顾目标的讨论**
  - Identify, assess and participate in resolving ethical dilemmas  
**识别、评估并参与解决伦理困境**
  - Advocacy and entitlements  
**倡导与授权**
  - Share in team support and team maintenance  
**团队支持与维系**
  - Evidence-informed interventions  
**循证干预**

## Education for the PELC Social Worker 纾缓治疗社会工作者的教育

- Most US social workers have master's degrees (MSW) and some are trained at the bachelor's level (BSW).  
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 is typical in the field of palliative and end-of-life care, a master's degree is typical in the field of palliative and end-of-life care, a master's degree is typical in the field of palliative and end-of-life care.
- Lack of training in palliative and end-of-life care in MSW education, most learn on the job and from colleagues in other disciplines.  
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，大部分是在工作中和向其他专业同事学习的
- 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, much only focused on death and grief  
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；很多只是侧重于死亡与哀伤

### 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	Post-Masters Certificate	Leadership Fellows
<ul style="list-style-type: none"> <li>• <i>Focused learning and career-building for students/beginning social workers</i></li> <li>• Enhanced field placements</li> <li>• Educational and case seminars</li> <li>• Mentorship and career guidance</li> <li>• Funding for conferences and professional development</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Enhancement of PELC competencies (knowledge, skills, and attitudes) for social workers early in their career</i></li> <li>• One-year intensive educational program</li> <li>• Courses promote integration of theory and practice</li> <li>• Capacity-building through development of over 150 experts in palliative social work</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Advanced professional development and mentorship for mid-career emerging leaders</i></li> <li>• Seminars in advanced topics in PELC practice, research, knowledge dissemination and leadership</li> <li>• One year of intensive mentorship</li> <li>• Capstone projects</li> </ul>

### Three Program Components 三个项目内容

MSW专业方向/ 奖学金	硕士(后) 证书课程	领袖项目
<ul style="list-style-type: none"> <li>• 着重学生/新入职社工的学习及职业建设</li> <li>• 加强临床实习</li> <li>• 培训课程或案例讨论会</li> <li>• 导师及职业规划</li> <li>• 资助参与专业研讨会及专业发展</li> </ul>	<ul style="list-style-type: none"> <li>• 提升社工在职业早期有关PELC的能力(知识,技巧及态度)</li> <li>• 一年密集型培训项目</li> <li>• 促进理论与实践融合的课程</li> <li>• 通过发展超过150个在PELC领域的专家,推动能力建设</li> </ul>	<ul style="list-style-type: none"> <li>• 为事业中期崭露头角的社工领袖提供进阶的专业发展及督导</li> <li>• 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</li> <li>• 一年的密集型指导</li> <li>• “顶点”(Capstone)项目</li> </ul>

### 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; role diffusion within team  
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?

### And How Did We Get Here 我们努力的过程

In the U.S. 在美国

1994 - Project on Death in America “死亡在美国”项目

- 1999 - funded needs survey which led to selection of 42 “Social Work Leaders” who submitted projects focused on practice, education, policy and research  
1999 - 资助需求调研, 引导选出42名“社工领袖”, 提交实践、教育、政策与研究项目计划
- Collaborated in funding Social Work Summits in 2002 and 2005  
分别于2002和2005年合作资助社工峰会
  - Engaged social work organizations and palliative care and end-of-life groups to support social work and set priorities and action plans  
吸引社工组织和PELC团体支持社会工作, 设立优先次序及行动方案
  - 2005 Summit - included international participants from Canada, England and Singapore  
2005年峰会 - 包括来自加拿大、英国和新加坡的国际与会者
  - Each followed by publications 每一项活动都有跟进的出版物

### But We Were Not in Isolation 但我们并不是孤立的

- Concurrent Projects in the U.S. & beyond  
目前在美国和国际上同时存在的项目
  - National Consensus Project 国家共识项目
  - Center for the Advancement of Palliative Care  
姑息治疗发展中心
  - World Health Assembly Resolution passed in 2014  
世界卫生大会于2014年通过决议
  - Institute of Medicine report on *Dying in America*  
美国国家科学院医学研究所关于“死亡在美国”项目的报告
    - Advocates for medical and social services  
倡导医疗及社会服务
  - National Quality Forum Preferred Practices  
国家质量论坛优质实践指南
  - Joint Commission certifications 联合委员会认证资格证书
  - And more 其它

### Within the Profession 专业范围内

- Standards and competencies evolved in the U.S., Canada and Europe 专业标准及能力要求在美国、加拿大及欧洲的发展
- Post MSW fellowships, while only a few, provide paid training opportunities  
硕士（后）培训项目，但只有少数项目提供有报酬的培训机会
- Certification established with support of national social work (NASW) and hospice organizations (NHPCO) 在全国社工协会、姑息治疗及临终关怀服务协会的支持下，设立资格证书
- Specialty training programs continuing to develop, some internet, some interdisciplinary 持续发展特别培训项目，一些是在线培训项目，一些是跨学科培训项目
- Email communication network connecting over 700 social workers in U.S. and beyond  
电邮沟通网络：连接全美国乃至海外700余名社工

### Symbols of Specialization 专业化的标志

- Enhance recognition across disciplines  
提升跨专业的认同
  - Social Work Hospice & Palliative Care Network  
姑息治疗及临终关怀社会工作协会
  - Journal of Social Work in End of Life and Palliative Care  
姑息治疗及临终关怀社会工作专业期刊
  - Oxford Textbook of Palliative Social Work  
牛津大学姑息治疗社会工作教科书
  - Current work focused on creating competency examination  
目前工作重点：设立能力资格考试

### Where Are We Now 目前状况如何？

- Evidence base continues to affirm clinical and cost effectiveness of palliative care  
实证为本继续证明姑息治疗的临床疗效及成本效益
- Increasing demand has fostered interest in defining primary and specialist practice  
持续增长的需求激发了对初级实践和专科实践进行定义的兴趣
- Leads social work to the beginning  
引导社会工作回归本源
  - The core values, skills and theories which inform the profession of social work have always cohered with palliative care principles  
社会工作专业核心价值观、技巧和理论与姑息治疗原则相一致
  - When "working to the top of our license"  
当“运用你所有的知识去追求最佳的表现”

How Does This Relate to Your Social Work Place and Practice  
这如何与你的社会工作机构及实践相关？

- How do you imagine the path to grow and enrich your presence and impact as primary clinicians and as specialists?  
对于发展和提升自己作为初级和专科临床工作者的存在感及影响力，你有和设想？
- What obstacles – internal and external- might you encounter on the path to enhancing care of patients and families and quietly and purposively integrating some of what is learned over these 3 days ?  
如果你有目的地将这两天所学知识应用于实践，提升对患者及其家人的照顾质量，你可能会遇到什么阻碍（内部和外部）？