

项目详细内容 Project Details:

项目名称	舒缓爱心家园对晚期肿瘤患者家属应对能力的干预		主题	晚期肿瘤患者家属
Project Title	The intervention of palliative love among terminal cancer patients		Theme	Hospice care
项目负责人	刘颖颜	项目成员 Project Team	奚晓君、杨敏、蒋申贞、计婷婷、张利娜	
Project Lead	LIU yingyan			
经费 Funding	RMB 1.2万			
项目起止日期 Project Period	起始: 2013年1月1日 Start Year Month Day		完成: 2013年12月30日 End Year Month Day	
问题描述 Problem Description 请描述问题起因及存在多久、问题形塑过程中的关键人员及人数。 请以中英文填写。	<p>面对死亡，任何人都不会有经验。晚期肿瘤患者家属在面对亲人临终阶段缺乏应对能力。</p> <p>2012年上海市最新数据显示，上海市每年新增肿瘤患者5.1万人；每年肿瘤患者死亡3.2万人，死亡率为238/10万，但是医院床位的开放不能满足晚期肿瘤患者的需求，使有些晚期肿瘤患者的临终最后阶段只能在家中度过，而患者家属缺乏照护技能及心灵抚慰能力，面对亲人离世而又无能为力。同年上海市政府实事项目中提出在全市各区县选择试点社区卫生服务中心设置舒缓疗护（临终关怀）科，为晚期肿瘤患者及家属提供居家和机构相结合的舒缓疗护服务。</p> <p>本中心作为舒缓疗护试点单位，2012年10月开始为晚期肿瘤患者提供舒缓疗护服务，同时，对患者家庭提供生死教育、心理支持、人文关爱、生活照顾技能等培训。我们通过组建服务团队12人，建立舒缓爱心家园，为60例晚期肿瘤患者家属提供系列干预措施。</p> <p>Facing death, anyone have experience. Family members of patients with advanced cancer in the face of loved ones dying stages of the lack of response capabilities.</p> <p>The latest data show that in 2012 in Shanghai, Shanghai, 5.1 million new cancer patients each year; 3.2 million people died of cancer patients each year, a mortality rate of 238/10 million, or hospital beds open but can not meet the needs of patients with advanced cancer, so some the final stage of dying patients with advanced cancer can only be spent at home, and family members of patients and lack of care skills, the ability to soothe the mind, but powerless to face the death of their loved ones. The same year, the Shanghai government practical projects proposed in the city's districts and counties to select pilot community health service centers set soothing palliative care (hospice) Division, provides a combination of home and</p>			

	<p>institutional palliative care services to relieve advanced cancer patients and their families.</p> <p>The center as a soothing palliative care pilot units, began in October 2012 to provide palliative care services to relieve advanced cancer patients, while the death of the patient's family to provide education, training psychological support, human love, life care skills. Our team of 12 people through the formation, establishment soothing loving homes, provides a series of interventions for 60 cases of family members of patients with advanced cancer.</p>
<p>解决方法 Solution 请描述可行的解决方法和形塑过程。 请以中英文填写。</p>	<p>运用 PSBH 的“解决问题、促进健康”的理念和方法，制定本课题的解决方案。</p> <p>通过建立舒缓爱心家园，课题组对入住迎博社区卫生服务中心舒缓疗护病房的晚期肿瘤患者家属进行为期 3-6 月的干预，提供生死教育、心理支持、人文关爱、生活照顾技能等培训，具体实行措施如下：</p> <ol style="list-style-type: none"> 1、课题组人员培训、明确分工 2、查阅文献、家属访谈，收集患者家属最感困惑的问题，设计疾病相关知识调查表。内容包括家属一般情况、心理状态，对舒缓疗护理念认知程度、生活照顾技能、躯体症状护理等。 3、研究对象：选择 2013 年 1-11 月入住本中心舒缓疗护病房的晚期肿瘤患者家属（主要照顾者）60 例。 4、纳入标准：①肿瘤患者卡氏评分（Karnofsky, KPS）评分≤70 分；预计其生存期 3 个月之内[3]；②家属自愿配合本研究；③家属学历在初中及以上；④家属接受舒缓疗护理念。 5、方法：建立舒缓爱心家园，入住舒缓疗护病房的晚期肿瘤患者家属都是舒缓爱心家园成员。纳入本研究的家属签订知情同意书，建立家庭信息档案，当场接受基线问卷调查。根据调查结果运用护理程序制定舒缓爱心家园计划，提供系列干预措施，干预时间为 6 个月。 <ul style="list-style-type: none"> （1）开展各种形式的健康教育活动 ①举办系列健康教育讲座每周 1 次，每次 30 分钟。内容包括：舒缓疗护理念、优死教育、肿瘤疾病相关知识、生活护理技巧等。②发放宣传手册 内容涵盖身、心、社、灵四个方面，包括舒缓疗护病区介绍、住院流程、舒缓疗护知识，病情告知、日常护理篇、症状护理篇等内容。③舒缓理念宣传板展示有心灵驿站、人文关爱、优死理念。

- (2) 生活照顾技能培训 以授课和技能演示相结合，内容：压疮预防、口腔、皮肤清洁、翻身搬运技巧、喂食技巧、有效排痰等。
- (3) 提供个性化心理疏导 包括：一对一的话聊、放松疗法、哀伤辅导等。
- (4) 爱心家园活动 举办生日祝福、金婚庆祝、端午送温馨、月月闻书香、
“爱与尊重”生命教育、一家亲欢乐派对、社区舒缓大讲堂等。
- (5) 社会支持 构建“舒缓爱心家园”网络平台，开通网站、QQ群、新浪微博栏目；与非营利组织合作，发挥志愿者优势，与国内外生命工作者互动；为患者家属提供信息支持和情感宣泄的平台。

6、干预培训后再次问卷调查。

7、收集资料整理、统计分析，撰写论文。

PSBH use of concepts and methods "to solve problems, promote health", the development of solutions to this problem.

Through the establishment of soothing loving homes, the research group of the check-Ying Bo community health centers to relieve families of patients with advanced cancer palliative care ward for a period from March to June of intervention, provide death education, training, psychological support, human love, life care skills, implement specific measures are as follows:

- 1, the group training, a clear division of labor
- 2, literature, interviews with family members, family members of patients to collect the most puzzling questions, questionnaire design disease-related knowledge. Including families in general, mental state, the concept of palliative care to relieve awareness, life care skills, physical symptoms care.
3. Subjects: Choose from January to November 2013 Check the Center soothing palliative care ward of advanced cancer families (primary caregiver) of 60 patients.
4. Inclusion criteria: ① cancer patients Karnofsky score (Karnofsky, KPS) score ≤ 70 points; their survival is expected within three months [3]; ② voluntarily with their families in this study; ③ families in junior high school education and above; ④ acceptance of the concept of palliative care to relieve their families.
5. Methods: soothing loving homes, family members of patients stay soothing palliative care wards caring homes with advanced cancer are soothing members. The families included in the study signed informed consent, a family information file on the spot to accept the baseline questionnaire. Use the survey results to develop a soothing loving home care program plan, provides a series of interventions, intervention time for six months.

(1) to carry out various forms of health education activities

- 1 series of health education seminars held once a week, every 30 minutes. Content includes: soothing palliative care philosophy, gifted education dead tumor disease-related knowledge, skills and other life care.
- 2 issued a brochure covers four areas of body, mind, social, spiritual, including palliative care ward soothing introduction, hospital procedures, soothing palliative care knowledge, inform the disease, daily care articles, symptom care articles

	<p>and other content. ○ 3 soothing philosophy billboards show had Xinlingyizhan, human caring, excellent idea dead.</p> <p>(2) life skills training to teach and care skills demonstration combining elements: prevention of pressure sores, mouth, skin cleansing, turning handling skills, feeding skills, such as effective expectoration.</p> <p>(3) to provide personalized psychological counseling include: one to one, then talk, relaxation therapy, grief counseling.</p> <p>(4) a caring home activities birthday wishes, golden wedding celebration, the Dragon Boat Festival to send warm smell scholarly month, "Love and Respect" life education, a pro-joy parties, communities and other soothing auditorium.</p> <p>(5) social support to build "a soothing love home" network platform, launched the site, QQ group, Sina microblogging column; cooperation with non-profit organizations, volunteers play advantage, interaction with domestic and foreign workers in life; to provide information support for family members of patients and emotional catharsis platform.</p> <p>6, after the intervention of training questionnaire again.</p> <p>7, collect data compilation and statistical analysis, writing papers.</p>																									
<p>成效 / 影响力 Outcome / Impact 请提供方案实施前的基线数据和实施后的成果指标。 请以中英文填写。</p>	<p>1. 干预前后晚期肿瘤患者家属疾病相关知识知晓情况 干预前后晚期肿瘤患者家属对疾病相关知识四个维度的认知程度均有显著性差异 (P<0.05)。见表 1。</p> <p>Family members of patients with advanced cancer disease related knowledge before and after the intervention in the families of patients with advanced cancer disease-related knowledge awareness of the four dimensions were significant differences (P <0.05) before and after 1. intervention. Table 1.</p> <p>Table 1 family members of patients with advanced cancer disease-related knowledge before and after the intervention (n = 60)</p> <p style="text-align: center;">表 1 晚期肿瘤患者家属疾病相关知识干预前后比较 (n=60)</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left;">维度 Score</th> <th style="text-align: center;">干预前 Before</th> <th style="text-align: center;">干预后 After</th> <th style="text-align: center;">t</th> <th style="text-align: center;">P</th> </tr> </thead> <tbody> <tr> <td>舒缓疗护理念 Soothing palliative care attitudes</td> <td style="text-align: center;">26.73 ± 3.51</td> <td style="text-align: center;">47.95 ± 4.12</td> <td style="text-align: center;">-8.25</td> <td style="text-align: center;"><0.01</td> </tr> <tr> <td>生活照顾技能 Daily care skills</td> <td style="text-align: center;">18.22 ± 1.14</td> <td style="text-align: center;">22.35 ± 1.98</td> <td style="text-align: center;">-6.85</td> <td style="text-align: center;"><0.01</td> </tr> <tr> <td>躯体症状护理 Somatic symptoms care</td> <td style="text-align: center;">20.76 ± 1.34</td> <td style="text-align: center;">27.24 ± 1.21</td> <td style="text-align: center;">-7.71</td> <td style="text-align: center;"><0.01</td> </tr> <tr> <td>心理状态 Psychological condition</td> <td style="text-align: center;">9.90 ± 0.66</td> <td style="text-align: center;">11.79 ± 0.57</td> <td style="text-align: center;">-2.35</td> <td style="text-align: center;"><0.05</td> </tr> </tbody> </table> <p>2. 干预前后 SAS 评分比较 晚期肿瘤患者家属干预前 SAS 阳性 27 名</p>	维度 Score	干预前 Before	干预后 After	t	P	舒缓疗护理念 Soothing palliative care attitudes	26.73 ± 3.51	47.95 ± 4.12	-8.25	<0.01	生活照顾技能 Daily care skills	18.22 ± 1.14	22.35 ± 1.98	-6.85	<0.01	躯体症状护理 Somatic symptoms care	20.76 ± 1.34	27.24 ± 1.21	-7.71	<0.01	心理状态 Psychological condition	9.90 ± 0.66	11.79 ± 0.57	-2.35	<0.05
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(45.0%)，干预后 SAS 阳性率 16 名(26.7%)，有显著性差异($p<0.01$)，见表 2。

2. SAS scores before and after the intervention compared to patients with advanced cancer families before the intervention SAS positive 27 (45.0%), SAS positive rate of 16 (26.7%), there was a significant difference ($p <0.01$), Table 2 after the intervention.

Table 2 SAS scores before and after the intervention (n = 60, patients)

表 2 干预前后 SAS 评分比较 (n=60, 例)

SAS	评分 Score
干预前 Before	47.78 ± 7.31
干预后 After	41.35 ± 6.08
t	-7.53
P	<0.01

3. 干预前后 SCSQ 评分比较 患者家属积极应对方式由干预前的 21.32 ± 5.06 提高到干预后的 23.58 ± 4.21，消极应对方式由干预前的 9.52 ± 3.76 下降到干预后的 8.01 ± 4.04。见表 3

表 3 干预前后 SCSQ 评分比较 (n=60, 例)

SCSQ scores between families of patients with positive coping around 3. intervention to improve before the intervention by 21.32 ± 5.06 to 23.58 ± 4.21 after the intervention, negative coping decreased from 9.52 ± 3.76 before the intervention to 8.01 ± 4.04 after the intervention. Table 3

Table 3 SCSQ scores before and after the intervention (n = 60, patients)

应对方式 Way of Response	积极应对 Positive attitude	消极应对 Negative attitude
干预前 Before	21.32 ± 5.06	9.52 ± 3.76
干预后 After	23.58 ± 4.21	8.01 ± 4.04
t	-8.91	9.37
P	<0.05	<0.05

4. 《舒缓爱心家园—亲善之家社区临终关怀服务建设》项目，获

2013年浦东新区总工会科技创新成果“先进操作法”入围奖。

5. 本人作为带教导师，培养浦东新区社区适宜人才1名。

6. 撰写本课题相关论文4篇

1) 发表2篇。(1) 舒缓爱心家园对社区晚期肿瘤患者家属应对能力干预，解放军护理杂志；(2) 舒缓照护的研究进展及思考，上海医药杂志。

2) 舒缓疗护（临终关怀）国际伦理大会论文交流1篇：叙事医学视角探索临终关怀伦理困境，获优秀论文奖。

3) 上海市社区卫生服务论坛大会交流论文1篇：叙事医学视角探索社区临终关怀护士培训新路径。

7. 制作的舒缓疗护系列健康教育手册《临终患者居家-住院生活指南》“身体照护”篇、“心”篇2本，对患者家属知识的传播起到了良好的作用。

8. 上海电视台、新闻综合1/7频道、浦东电视台、ICS电视台、新闻网、浦东时报、新民晚报、解放日报、大众卫生报等多家新闻媒体采访报道30余次，上海市、区县领导和同道多次参观舒缓疗护分享交流经验。

9. 源于对舒缓疗护的热爱和付出，2014年5月获得上海市“左英护理奖”提名奖。

4. "Love soothing home - home hospice services building goodwill of the community" project, won the 2013 Federation of Trade Unions, Pudong New Area, technological innovations "advanced operation of law" Finalist.

5. I have a teaching mentor, train, Pudong New Area community a suitable talent.

6. Write the subject related papers 4

1) published two. (1) to relieve a caring home for families of patients with advanced cancer community capacity to respond to the intervention, the magazine of the PLA care; (2) to relieve progress and thinking, Shanghai care of Medicine study.

2) soothing palliative care (hospice) International Bioethics Conference papers exchange one: the narrative perspective of exploring hospice medical ethical dilemmas, won the best paper

	<p>award.</p> <p>3) Shanghai Community Health Service Forum Congress exchange papers 1: Narrative Medicine Perspective Community Hospice Nurse Training explore new paths.</p> <p>7. produced a series of health education soothing palliative care Handbook "dying patients at home - hospitalized Guide to Life," "Body Care" chapter, the "heart" chapter two, family members of patients to disseminate knowledge played a good role.</p> <p>8. Shanghai television news channel integrated 1/7, Pudong TV, ICS Television, News, Pudong Times, the New People's Daily, Liberation Daily, public health reporting and many other news media coverage, more than 30 times, in Shanghai, the county leadership and palliative care to relieve fellow repeatedly visited the exchange of experiences to share.</p> <p>9. soothing palliative care stems from the love and dedication, May 2014 Shanghai was "left England Care Award" nomination.</p>
<p>执行力 Excellence in Execution</p> <p>请提供评价标准(如时间、预算、人力、干预族群的满意度), 及计划初始估计与成果的比较。例: 规划运行4个月, 800人民币。实际为4个月, 花费680人民币。 请以中英文填写。</p>	<p>1. 本项目规划研究日期为1年, 项目如期完成;</p> <p>2. 经费预算1.2万元人民币, 实际花费1万元;</p> <p>3. 课题组人员6人, 单位在人力、物力、设备等给予大力支持。</p> <p>4. 研究对象的满意度达100%。</p> <p>5. 本项目研究目标按期完成, 显著超过预期成果。</p> <p>1. The project was completed on schedule of a one year duration. 2. The budget of 12,000 yuan, the actual cost of 10,000 yuan; 3. Task Force staff of six units in manpower, equipment, etc. to give support. 4. Satisfaction study of up to 100%. 5. The research objective of this project is completed on schedule, significantly more than the expected results.</p>
<p>发展性 Sustainability</p> <p>请描述如何持续项目成果, 及在其他区域的可复制性。例: 若需在五个社区复制此方案, 需要的策略合作伙伴为乙方及丙方, 估计需要五千人民币, 可能从以下三个单位获取, 及资金取得的时间表。</p>	<p>1. 持续项目: 《舒缓疗护社区护士培训的效果评价》, 2014年8月获浦东新区卫计委立项, 给予4万人民币研究经费资助。</p> <p>2. 社区舒缓疗护服务实践, 2014年在浦东新区13家社区卫生服务中心推广。</p> <p>1. Continuous Project: "soothing palliative care community nurses evaluate the effectiveness of training," August 2014 is eligible Pudong New Area</p>

<p>请以中英文填写。</p>	<p>Health Planning Committee, to give 40,000 yuan research funding. 2. Community soothing palliative care service practice, in 2014 in the Pudong New Area, 13 community health centers to promote.</p>
<p>创新力 Innovation 请描述方案执行中遇到的挑战、应对过程及方式。 请提供任何项目执行的相关照片、影片。如前后的比较、干预对象、宣教范本等。 请以中英文填写。</p>	<p>1. 舒缓疗护服务模式新颖，具有示范作用：晚期肿瘤患者家属对舒缓疗护理念的认知程度普遍较低，传统文化影响着人们的死亡观，对死亡采取负面态度，而“孝道”使多数人认为把患者送到临终关怀机构，一方面会影响儿女尽孝道，另一方面认为是放弃治疗，感情上难以接受。我们采取的应对方式是舒缓疗护理念的相关教育和宣传、个性化心理疏导，使得大部分患者家属逐步理解舒缓疗护理念，积极配合本项目计划的实施。</p> <p>2. 构建舒缓爱心家园网络信息平台在全市社区具有创新意义，通过微博、QQ官方网站传播舒缓疗护的理念，介绍实践经验，为癌症临终患者家庭成员提供延续性支持。</p> <p>3. 与社会组织“上海手牵手生命关爱发展中心”合作模式具有创新性，发挥志愿者优势，整合资源、给予临终患者及家属情感支持和家庭关系的调适，为探索社区志愿者临终关怀协同服务提供相关经验。</p> <p>1. soothing new palliative care service model, with a demonstration effect: the families of patients with advanced cancer awareness of palliative care to relieve the concept is generally low, the traditional culture influences people's view of death, for death to take a negative attitude, and "filial piety" make Most people think of the patient to the hospice agency, on the one hand will affect filial sons and daughters, on the other hand thought to give up treatment, emotionally difficult to accept. We take the coping is related to education and information, personalized palliative care to relieve psychological counseling concepts, making most of the family members of patients develop an understanding of the concept of palliative care to relieve, and actively support the implementation of the project plan.</p> <p>2. Building a loving home network information platform soothing innovative community in the city, through the micro Bo, QQ official website spread soothing palliative care philosophy, introduce practical experience for dying cancer patients Family members who provide continuity of support.</p> <p>3. Social Organization "Shanghai Hand in Hand Life Care Development</p>

	Center" cooperation model is innovative, volunteers play the advantages of integration of resources, to give emotional support to patients and their families adapt and family relations deathbed, to explore collaborative community volunteer hospice services provide relevant experience.
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