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晚期肿瘤姑息放疗护理中共享决策的伦理意蕴与实践路径

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摘　要

目的：探讨共享决策在晚期肿瘤姑息放疗护理中的伦理基础、实践困境与推进策略，为构建本土化终末期护理决策模式提供参考。方法：基于伦理学理论与我国姑息放疗临床情境，通过文献分析与理论思辨，系统梳理共享决策的核心要素、伦理意蕴及实践路径。结果：共享决策在姑息放疗护理中呈现为信息传递、价值澄清至协商共识的渐进过程，护理人员承担信息中介与价值协调者角色；其伦理基础涵盖从程序性知情向实质性赋权的转变、获益与负担权衡中的伦理相称性，以及关怀伦理视域下对患者情感需求的回应。当前实践面临家庭决策主导与患者自主权的文化张力、治疗预期错位与信息传递的伦理两难、结构性沟通约束及本土化决策辅助工具匮乏等多重困境。结论：建议构建基于价值观评估的决策前置机制，开发图形化与标准化决策辅助工具，推行护士主导的多学科协作模式，并建立贯穿治疗全程的持续性评估与动态反馈框架，以推动共享决策的本土化落地，实现患者决策尊严与生命质量的协同保障。

关键词

共享决策，姑息放疗，晚期肿瘤，护理伦理，终末期照护

Ethical Implications and Practice Pathways of Shared Decision-Making in Palliative Radiotherapy Nursing for Advanced Cancer

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Abstract

Objective: To explore the ethical foundation, practical dilemmas, and promotion strategies of shared decision-making (SDM) in palliative radiotherapy nursing for advanced cancer, providing a reference for constructing a localized end-of-life nursing decision-making model. Methods: Based on ethical theories and the clinical context of palliative radiotherapy in China, the core elements, ethical implications, and practice pathways of shared decision-making were systematically elaborated through literature analysis and theoretical reflection. Results: Shared decision-making in palliative radiotherapy nursing manifests as a progressive process from information transfer and value clarification to negotiated consensus, with nursing professionals serving as information intermediaries and value coordinators. Its ethical foundation encompasses the transition from procedural informed consent to substantive empowerment, ethical proportionality in the weighing of benefits and burdens, and the responsiveness to patients' emotional needs from the perspective of care ethics. Current practice confronts multiple dilemmas, including the cultural tension between family-dominated decision-making and patient autonomy, ethical dilemmas arising from misaligned treatment expectations and information delivery, structural communication constraints, and the scarcity of localized decision aids. Conclusion: It is recommended to establish a pre-decision mechanism grounded in values assessment, develop graphical and standardized decision aids, implement a nurse-led multidisciplinary collaborative model, and construct a continuous assessment and dynamic feedback framework throughout the entire treatment course, thereby promoting the localized implementation of shared decision-making and achieving coordinated safeguarding of patients' decisional dignity and quality of life.

Keywords

Shared Decision-Making, Palliative Radiotherapy, Advanced Cancer, Nursing Ethics, End-of-Life Care

1. 引言

舒缓医疗的兴起推动了晚期肿瘤照护目标的深层转变，从单纯延长生存周期转向维护生命末期的质量与尊严[1]。在这一背景下，姑息性放疗因能有效缓解骨转移疼痛、腔道梗阻及肿瘤出血等症状，已成为终末期症状管理的重要干预手段[2]。然而，该治疗本身存在获益边界模糊与毒性损伤不可逆的特点，患者实际上面临着过度干预与支持不足的双重风险[3]。传统的家长式决策模式通常将患者置于被动接受位置，其个体价值观与生活目标难以进入临床考量，这在终末期复杂情境中已显露出明显局限[4]。共享决策(shared decision-making, SDM)通过建立医护患之间的信息对等、价值整合与共识协商机制，为肿瘤专科护理介入终末期决策提供了可操作的路径。鉴于此，本文结合我国姑息放疗的临床实际，系统梳理共享决策在该领域的伦理基础、实践困境及推进策略，以期为构建本土化的终末期护理决策模式提供参考。

2. 共享决策的核心要素与护理特殊性

在姑息放疗护理情境中，共享决策通常经历一个由信息传递、价值澄清到协商共识的渐进过程[5]。

临床团队需向患者充分披露放疗的预期获益、潜在毒性及可行的替代方案[6]；护理人员在此过程中发挥信息中介作用，借助决策辅助手段降低专业信息壁垒，并运用叙事护理技术引导患者梳理自身价值序列，使其在生存质量与治疗风险之间作出符合个体意愿的权衡[7]。由此形成的决策共识并非静态结果，而是医学证据与患者当下价值观的动态整合[8]。在姑息护理的整体框架下，这种共识自然延伸至对治疗中止或放弃的伦理接纳[9]。

与以肿瘤控制为首要目标的根治性放疗不同，姑息放疗的核心在于症状缓解与舒适维护，这要求护理评估的重心从肿瘤退缩率等生物医学指标，转向症状控制满意度及生命尊严的维护[10]。与此同时，姑息性干预本身存在双重效应[11]。治疗所需的高频往返与等待过程可能侵蚀患者有限的居家时间，而放射性毒性在短期内甚至可能加剧躯体痛苦[12]。加之在中国家庭伦理语境中，家属基于孝道观念的保护性医疗倾向常与患者的知情权形成张力，上述多重不确定性使得任何单一的专业判断都难以推导出普适的最优解，共同决策因而成为必要路径[13]。

在传统肿瘤放疗模式中，护理工作多局限于方案执行与并发症监测[14]。进入姑息决策领域后，护士的角色发生实质性拓展[15]。其需要将抽象的循证数据转译为与患者日常生活质量直接关联的具体信息，敏锐识别患者的真实偏好并及时反馈至医疗团队[16]；当医生的治疗倾向、家属的过度干预与患者自身的舒适诉求发生冲突时，护士应以患者利益代言人的身份介入，维护其在生命末期的伦理自主性[17]。

3. 共享决策的伦理基础

3.1. 从程序性知情向实质性赋权

现行姑息放疗实践中的知情同意往往异化为形式化的文书流程[18]。患者在躯体衰弱、死亡恐惧及信息过载的多重压力下，其签署行为多属被动配合，实质上仅完成了法律层面的风险告知程序，而未能实现真正意义上的自主决策[19]。共享决策则将知情理解重构为一个持续的协商与对话过程，通过渐进式的信息传递与意义阐释，逐步消解医患之间的信息不对称，使最终选择建立在患者充分认知的基础之上[20]。在家庭本位的文化语境中，患者的真实意愿常被家属的代理决策所遮蔽[21]；护理人员通过系统性的价值观澄清，协助患者辨识并表达自身的生命目标与治疗偏好[22]。当家属的保护性干预与患者的真实诉求发生冲突时，共享决策提供了制度化的沟通与协调机制，以确保决策结果能够回应患者的核心生命价值，降低其决策后的遗憾感，维护其在生命末期的主体性与尊严[23]。

3.2. 获益与负担权衡中的伦理相称性

姑息放疗在缓解症状的同时，亦伴随明确的毒性损伤，其临床决策本质上是一种基于个体价值序列的动态权衡[24]。传统肿瘤学评估多依赖客观疗效指标，但终末期患者对治疗价值的主观判断存在显著异质性，统一的医学标准难以替代个体的价值排序[25]。共享决策要求将疗效评估嵌入患者的整体生活目标之中，并充分披露那些易被忽视的隐性治疗成本[26]。对于预期生存时间有限的患者而言，反复往返医院所耗费的时间与精力，本身即构成不可忽视的治疗负担[27]。当患者基于自身价值判断，认定干预负担已超出预期的生活质量改善时，共享决策赋予其拒绝继续放疗、转向安宁疗护的伦理正当性，从而尊重其在生命末期的自主决定权[28]。

3.3. 在关系中守望与对情感需求的伦理回应

关怀伦理学主张，医疗决策不应脱离具体的人际关系情境、情感叙事以及对人类脆弱性的回应[29]。晚期肿瘤患者除承受死亡焦虑与治疗情境外，还常因疾病给家庭带来的照护负担而产生道德压力与自责情绪[30]。护理人员须具备充分的伦理敏感性，透过患者表面的临床陈述，识别其背后未被言明的情感需

求，并以持续性陪伴分担其决策过程中的心理负荷[31]。当患者最终决定放弃放疗并转入舒缓疗护时，护理人员的无条件接纳、非评判性态度以及持续性的情感支持，能够为患者提供深层的伦理慰藉[32]。从关怀伦理的视角审视，共享决策在此并非单纯的治疗方案选择工具，而是护理学作为关系性照护实践的具体呈现[33]；它要求护士在患者的生命终末期，以伦理敏感性与情感回应能力，守护其作为完整的人的尊严与需求[34]。

4. 实践困境

4.1. 家庭决策主导与患者知情权的张力

共享决策的理论预设以个体自主为基石，但在中国医疗场域中，家庭往往在治疗决策中占据主导地位[35]。家属基于孝道伦理或保护性动机，常要求对病情及预后信息采取限制性披露，甚至直接替代患者作出决定[36]。这种模式下，患者的知情权与参与权事实上被悬置[37]。护理人员若顺应家属意愿采取模糊化沟通，虽可暂时维持家庭表面的和谐，却可能损害护患之间的信任基础，并使患者失去在生命末期处理个人事务、表达真实意愿的机会[38]。如何在尊重家庭决策文化的同时保障患者的主体地位，是姑息放疗共享决策本土化实践中需要审慎处理的核心张力。

4.2. 治疗预期错位与信息传递的伦理两难

在治疗预期层面，患者及家属常将姑息性放疗误解为具有根治潜力的干预手段[39]。这一认知偏差的形成有多重原因：一方面，“姑息”一词在中文语境中带有消极意涵，医护人员为避免刺激患者常倾向于使用委婉表述，客观上模糊了治疗目标的边界[40]；另一方面，面对死亡威胁时，患者的心理防御机制使其倾向于将局部症状的缓解放大为整体病情的好转[41]。加之正向信息更容易获得认知优先性，患者往往对治疗的时间成本及生理损耗关注不足[42]。对于护理人员而言，如何在诚实告知与保护希望之间把握分寸，成为日常实践中难以回避的伦理张力。过度强调疾病的不可逆性可能构成对患者心理希望的剥夺，而放任不切实际的预期则又有违专业诚信。

4.3. 结构性约束对深度沟通的抑制

从组织层面看，放疗科室的护理人力资源配置通常以技术操作为核心，深度沟通与决策辅助在现有工作排序中处于相对边缘位置[43]。现行绩效评价体系侧重可量化的护理技术指标，对决策支持、心理疏导等难以直接测量的工作内容缺乏有效激励，这在一定程度上抑制了护理人员投入共享决策的积极性[44]。此外，放疗区域的物理空间设计以治疗流转效率为导向，缺乏可供私密、深入交谈的独立环境，临终决策讨论往往只能在走廊或多人病房等开放空间进行，信息交换的充分性与严肃性难以得到保障[45]。

4.4. 决策辅助手段的本土化不足

在工具层面，目前适用于姑息放疗情境的决策辅助手段仍然匮乏[46]。现有国际开发的决策辅助工具多基于个人主义文化背景，未能充分回应中国家庭中患者自主与家属参与之间的平衡需求，也缺乏引导双方关注生命末期舒适度而非单纯生存时长的本土化评估维度[47]。同时，现有肿瘤决策支持工具多针对化疗或手术场景设计，专门针对姑息放疗获益与代价权衡的精细化模型尚属空白，尤其缺乏对治疗往返时间成本与患者剩余生存时间比例关系的量化评估工具，使得共享决策缺乏可操作的技术支撑[48]。

5. 实践路径

5.1. 构建基于价值观评估的决策前置机制

建议在姑息放疗方案确立之前，即引入基于价值观评估的决策前置机制[49]。通过结构化的价值观澄

清工具，将患者对生命质量的抽象诉求转化为可讨论的具体维度，包括延长生存与当下生活质量的优先级、对不良反应的耐受阈值、住院治疗与居家陪伴的空间偏好，以及对个人尊严需求的界定[50]。护理人员可在多学科团队制定放疗计划前完成此项评估，借此判断患者的决策准备度，并识别其尚未明确表达的治疗顾虑与内在冲突。考虑到晚期患者的价值排序常随疾病进展而动态变化，有必要建立周期性的回顾与更新机制[51]；当患者体能状态显著下降、无法耐受既定方案时，更新后的价值观评估结果可作为调整治疗策略、终止无效医疗或启动安宁疗护转诊的重要依据。

前述临床情景一中的患者陈某，若在放疗方案确立前引入价值观前置评估，责任护士可借助结构化价值观澄清工具，引导患者就“延长生存与当下生活质量的优先级”“对不良反应的耐受阈值”“住院治疗与居家陪伴的空间偏好”等维度进行排序。评估发现，患者将“减少往返医院的疲惫”与“在家人的陪伴中度过剩余时间”列为最高优先级，而将“尽可能延长生存”置于次要位置。该评估结果在多学科团队制定放疗计划前即被提交讨论，团队据此判断患者对姑息放疗的决策准备度有限，其真实诉求更倾向于低干预的舒缓疗护。经与家属召开结构化家庭会议，重新协商后，患者选择减少放疗次数、增加居家镇痛支持，实现了治疗决策与个体价值排序的匹配。此案例表明，价值观前置评估能够将患者抽象的意愿转化为可讨论的临床语言，为后续方案调整提供伦理依据。

5.2. 开发图形化与标准化的决策辅助工具

决策辅助工具的开发应兼顾标准化与可视化，以降低专业信息向患者传递过程中的认知损耗[52]。工具设计可采用风险与获益矩阵图，直观呈现不同干预方案的症状缓解概率与毒性风险，同时将时间成本转化为显性指标进行横向比较[53]。针对患者常将放疗视为唯一选择的锚定偏差，工具需设置并列的决策分支，将姑息放疗与最佳支持治疗、安宁疗护等替代方案同步呈现，明确各选项在终末期照护中的伦理正当性[54]。此类工具可进一步拓展为数字化交互界面，护理人员通过追踪患者的浏览时长与信息关注焦点，识别其决策盲区与核心顾虑，据此形成个体化的共享决策护理路径[55]。

5.3. 推行护士主导的多学科决策模式

在组织层面，建议建立以护理人员为协调核心的多学科共享决策机制[56]。护士凭借其在连续性照护中积累的患者信息，承担决策协调者角色，负责整合医学证据、日常照护观察及患者生活质量诉求，并将其转化为多学科讨论的核心议题[57] [58]。团队内部依专业特长分工协作，放疗医师提供循证医学证据与疗效评估，心理专业人员针对患者及家属的疗效预期偏差、保护性隐瞒等认知与行为问题进行干预，社会工作者则从家庭照护能力、经济承受力及社会支持网络等维度提供评估[59]。鉴于中国医疗情境中家庭常主导决策的文化特点，护士可定期组织结构化家庭会议，在促进信息透明的同时，为患者创造表达真实意愿的安全空间，并借助心理社会支持缓解家属的决策压力。该模式的可持续运作有赖于制度层面的配套，包括将决策支持与沟通协调纳入高级护理实践的职能范畴及绩效评价，并制定明确的临床操作路径。

针对临床情景三所呈现的走廊仓促沟通问题，若建立以护理人员为协调核心的多学科决策机制，责任护士李某可在当日治疗结束后，通过预约系统安排 30 分钟的标准化家庭会议，邀请放疗医师、心理师及社工共同参与。会议中，护士首先汇报连续照护中观察到的患者疼痛变化与情绪状态；放疗医师提供关于毒性累积的循证评估；心理师针对家属的疗效预期偏差进行认知干预；社工评估患者居家照护条件。护士作为协调者，确保患者“希望了解真实病情”的诉求在会议中被充分表达，并引导家属从“保护性隐瞒”转向“陪伴性告知”。会后，团队形成书面决策共识，明确后续治疗目标为症状控制而非肿瘤消退，并制定退出机制。该案例显示，护士主导的 MDT 模式能够将碎片化的走廊沟通转化为结构化的决策协商，但其可持续运作依赖于制度化的会议预约流程与工时核算。

5.4. 建立持续性评估与动态反馈的护理框架

鉴于姑息放疗患者的躯体功能与预后具有高度动态性，共享决策不宜被视为一次性完成的节点，而应作为贯穿治疗全程的持续性过程[60]。护理人员可整合电子化患者报告结局 ePRO (electronic patient-reported outcomes)系统，指导患者对治疗期间的疼痛、疲乏、营养状况及情绪变化进行实时记录[61]；当体力状态评分出现显著下降，或放射性损伤超出预设耐受范围时，自动触发决策再评估程序[62]。通过定期价值观回访，护理人员需向患者及家属重申治疗选择的可逆性与退出权，确保后续干预始终基于患者当下的真实意愿与客观获益评估。同时，护理人员作为信息枢纽，应建立院内评估数据与居家监测结果的实时同步机制，使患者在家庭休养期间的病情波动能够及时反馈至决策团队，纳入后续方案调整的综合考量[63]。

6. 现实障碍与分阶段推进策略

前文所述之价值观前置评估、可视化决策辅助、护士主导的多学科协作及持续性动态反馈，构成了一套逻辑自洽的理想化路径。然而，将这一模式嵌入当前中国医疗体系，须直面制度、文化、资源与专业能力四个层面的现实障碍。这些障碍并非孤立存在，而是相互嵌套、彼此强化，决定了共享决策的本土化不可能一蹴而就，而需经历一个分阶段、多层次的渐进过程。

6.1. 制度性障碍：护理协调角色的权责模糊

当前医疗管理体系中，护理人员在共享决策中的协调者角色缺乏明确的制度授权与执业规范[64]。我国《护士条例》虽规定护士有参与患者照护决策的权利，但未明确其在多学科团队中的决策协调职能，亦未设立对应的护理决策咨询收费项目[65]。在现有 DRG/DIP 支付框架下，决策支持、价值观澄清等无形劳动难以纳入绩效核算，导致护理管理者在人力配置时倾向于优先保障可量化的技术操作岗位[66]。此外，护士主导的家庭会议目前缺乏标准化的医疗文书模板，其决策记录的法律效力尚未明确，这使得护理人员在承担协调角色时面临潜在的职业风险[67]。制度层面的权责模糊，直接导致了护士在共享决策中“有责无权”的结构性困境。

6.2. 文化与组织障碍：家庭主义与科层结构的双重约束

中国医疗场域中的家庭主义文化不仅体现为患者家属对决策权的实际掌控，更深层地表现为一种“孝道”伦理下的保护性医疗传统[68]。即便护士通过价值观澄清协助患者表达了真实意愿，家属仍可能以“为了老人好”为由否定其选择，而护理人员缺乏有效的制度性支持来对抗这种家庭意志[69]。同时，医院内部的科层结构使护士长期处于医嘱执行者的从属地位，其建议需通过医生确认方能进入正式决策流程，这种“专业等级”无形中削弱了护士在共享决策中的话语权[70]。在姑息放疗情境中，当护士识别出患者拒绝治疗的意愿与家属坚持治疗的决定冲突时，往往只能诉诸“汇报医生”而非直接启动协调机制，导致决策延迟与患者意愿的进一步边缘化。

6.3. 资源与能力障碍：人力缺口与专业培训滞后

我国肿瘤专科护患比长期低于发达国家水平，放疗科护士每日承担大量技术操作，难以抽出整块时间进行深度决策沟通[71]。调查显示，多数放疗科护士未接受过系统的决策辅助培训，对价值观澄清工具、决策冲突调解技巧及伦理案例分析方法的掌握有限[72]。现有的继续医学教育项目仍以专科护理技术为重点，共享决策、叙事护理等人文胜任力的培养处于边缘地位。此外，适合中国文化情境的决策辅助工具开发需要跨学科团队长期协作，而目前此类研究项目难以获得临床科室的优先资源支持，导致本土化工具开发停留在学术构想阶段。

6.4. 分阶段推进策略

鉴于上述障碍的系统性，推行护士主导的共享决策不宜采取“一刀切”模式，而应建立短期验证、中期嵌入、长期制度化的三阶段策略。

短期，在具备姑息放疗资质的三甲医院肿瘤科遴选试点单元，组建“护士－社工－心理师”三人决策支持小组，在现有工作框架内嵌入 30~60 分钟的结构化决策访谈，同步开发简版价值观清单与图形化决策辅助单页。此阶段重点验证流程可行性，积累本土案例，而非追求全面铺开。中期，将决策支持工时纳入护理绩效评价的软性指标，建立护士主导的 MDT 决策会议制度与标准化记录模板；联合高校开发针对中国家庭的决策辅助工具包，开展多中心临床验证；在肿瘤专科护士认证体系中增设“决策辅助与伦理沟通”模块，建立分层培训机制，提升护士的决策协调能力。长期，推动护理决策协调职能纳入卫生政策与医保支付体系，探索决策咨询的独立收费项目；通过学术倡导与公众教育，逐步重塑社会对家庭决策与患者自主权关系的认知，使共享决策从科室层面的创新实践上升为终末期照护的制度标准。唯有经历这一渐进过程，理想化的共享决策路径方能从纸面构想转化为可操作的临床现实。

7. 结语

在晚期肿瘤姑息放疗领域，引入共享决策并非简单的流程增补，而是对终末期照护目标的重新校准[73]。当医学干预的获益边界趋于清晰且有限时，患者的主观体验与价值排序理应成为临床决策的核心参照[74]。价值观前置评估、可视化决策辅助、护士主导的多学科协作及持续性动态反馈，构成了一个从决策准备到方案调适的连续支持系统；其实质在于通过制度化的沟通机制，将患者的个体诉求有效嵌入临床决策全过程。然而，这一模式的本土化落地仍面临文化适应与资源配套的双重挑战[75]。制度权责模糊、家庭主义约束、人力与能力缺口，提示理想路径的推行必须经历一个分阶段、多层次的渐进过程：从试点单元的流程验证，到绩效评价与培训体系的制度嵌入，再到政策层面的职能确认与支付保障。未来的推进有赖于护理教育中决策辅助能力的培养、契合中国家庭伦理情境的工具开发，以及将共享决策程序纳入姑息放疗标准临床路径的制度设计，从而在终末期医疗中实现患者决策尊严与生命质量的协同保障。

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