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POLICY FORUM

Strategies for Promoting High-Quality Care and Personal Resilience in Palliative Care

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Abstract

Palliative care (PC) clinicians are faced with ever-expanding pressures, which can make it difficult to fulfill their duties to self and others and lead to moral distress. Understanding the pressures that PC clinicians face and the resources that could be employed to ease their moral distress is crucial to maintaining a healthy PC workforce and to providing necessary PC services to patients. In this paper, we discuss recommendations related to two promising pathways for supporting PC clinicians in providing high-quality PC: (1) improving systemic PC delivery and (2) strategies to promote ethical practice environments and individual resilience. Enacting these recommendations holds promise for sustaining higher-quality and accessible PC and a more engaged PC workforce.

Introduction

Palliative care (PC) clinicians are faced with ever-expanding pressures, which can make it difficult to fulfill their duties to self and others. In 2008, more than 90 million Americans were living with serious illness, and this number was projected to double in 25 years [1]. PC clinicians are tasked with reducing the suffering of these patients and face daily challenges, such as treating patients with intractable pain, facilitating end-of-life (EOL) decision making, and collaborating with other health care specialists to ensure that PC is sufficiently integrated [2]. A recent survey found that PC physicians who were planning to leave the profession commonly cited burnout or dissatisfaction with their organization or practice as the reason [3], and another study found that high moral distress is linked to clinicians' intentions to leave their current position [4].

Moral distress has been described as "one or more negative self-directed emotions or attitudes that arise in response to one's perceived involvement in a situation that [one] perceives to be morally undesirable" [5]. PC clinicians have a duty to relieve suffering, but they also have a duty to follow the wishes of patients and their surrogates, which can lead to what PC clinicians view as furthering unjust patient suffering when, for example, aggressive acute care is pursued beyond the point at which its clinical benefits justify its risks [6]. Among nurses in critical care and oncology settings, moral distress has also

been linked to nurses' knowledge that PC is effective in relieving patients' suffering but is unavailable due to a deficiency of environmental, human, or material resources [6, 7]. Furthermore, in a recent survey the majority of physicians and nurses reported that the situations most responsible for their moral distress are (1) following families' wishes to continue life support when the clinician believes it is not in the patient's best interests and (2) initiating life-saving action that the clinician believes would only prolong death [4]. Without effective PC, patients might continue to receive aggressive acute care and suffer the associated pain and other symptom burdens. Although moral distress has been identified in PC clinicians, there is very little in this body of research that points to a solution to the moral distress epidemic.

Understanding the pressures PC clinicians face and the resources that could be employed to ease their moral distress is crucial to maintaining a healthy PC workforce and to providing necessary PC services to patients. We will discuss these goals in connection with two promising pathways for supporting PC clinicians in providing high-quality PC: (1) improving systemic PC care delivery and (2) strategies to promote ethical practice environments and individual resilience.

Improving Palliative Care Delivery

Improving integrated PC is critical because there are limited PC fellowship training programs for physicians in the US, with fewer than 250 graduates per year and an estimated shortage of 18,000 PC physicians [3]. To address the need for more integrated PC, many leaders, academics, and organizations have called for the institution of high-quality PC across the health care spectrum. Notably, the National Academy of Medicine released a landmark report, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, in 2015 [8]. This report made specific recommendations for improving EOL and PC in the United States.

One of the primary recommendations of the report was to make PC a thread in health care education so that every clinician, regardless of specialty, would be capable of providing basic palliative care services. Currently, physicians and medical residents report that palliative care training is inadequate [9], and there is a common view among practicing clinicians that palliative care is only appropriate for patients who have stopped curative treatment, which prevents many patients who would benefit from PC from receiving it [10]. The nursing profession has made an effort to provide nurses with palliative care training through the End-of-Life Nursing Education Consortium (ELNEC), which has resulted in over 550,000 nurses receiving education in PC in 88 countries [11]. Despite the impact of the ELNEC program, there is still a need for more nurses with PC expertise, as suggested by the American Association of Colleges of Nursing recently releasing specific PC competencies for undergraduate nursing education [11]. Increasing palliative care knowledge across the health care workforce can improve communication between clinicians and patients, expand the number of patients who receive the range of

PC services—such as control of pain and other distressing symptoms and goal setting—and decrease both misinformation about PC and prominent sources of moral distress associated with end-of-life care [4, 10].

Furthermore, even though there is broad consensus that high-quality PC is necessary for patients with serious illnesses [8], there is a paucity of research on the specific patient outcomes that are necessary to achieve high-quality palliative care. In a recent review and meta-analysis, the authors concluded that the data do not support an association between specific PC processes and patient outcomes [12]. The National Academy of Medicine convened a panel of PC experts to propose specific components of high-quality EOL care (e.g., managing symptoms and emotional distress) [8], which could aid institutions and PC clinicians in planning and implementing PC programs and enable evaluation and data collection across health care systems.

Better understanding of these core components and the outcomes associated with them may lead to the incorporation of palliative care into routine treatment of serious illnesses as a matter of protocol, which could be particularly useful in the cancer setting [10, 11]. Oncology clinicians commonly use treatment protocols that map a course of treatment but allow for changes based on each patient's clinical course. Having a PC treatment protocol that operated in the same way could ensure that all cancer patients receive high-quality individualized PC along with their cancer treatment [13, 14]. Currently, patients with serious cancer diagnoses are underreferred for PC [15]; including PC earlier in the disease process is considered important for reducing patient suffering, clarifying goals of care [16], and reducing moral distress in clinicians [4]. An environment supportive of PC might also reduce the higher levels of moral distress experienced by clinicians trained in EOL care. For example, one survey of 592 interprofessional clinicians in a large tertiary medical center found that clinicians with specialized training in EOL care experienced higher moral distress than their colleagues who did not have this training [17]. While this finding might seem counterintuitive, the authors concluded that when clinicians are trained in providing high-quality EOL care, they likely become more aware of their obligations and duties to patients and their family members and therefore experience moral distress when they practice in a setting where it is not possible to fulfil these duties. Further research is needed to describe moral distress in clinicians in the context of high-quality PC and EOL care.

Promoting Ethical Practice Environments and Individual Resilience

While implementing high-quality palliative care may be an important tactic to address PC clinicians' moral distress on a systemic level, there is an urgent need to ensure that individuals have the <u>personal resources</u> to enact resilience on a day-to-day basis. The concept of resilience first emerged in the pediatrics literature to describe children who were able to thrive despite adverse circumstances [18]. Since its introduction, the concept of resilience has been studied in a diverse array of settings and populations [18].

Among health care workers, resilience-enhancing interventions have been demonstrated to have positive impacts on employee mental health and well-being, goal attainment, productivity, and performance [19]. And a recent pilot study conducted with PC clinicians found that a resilience-enhancing intervention was associated with reductions in perceived stress and improvements in perspective taking [20]. It stands to reason that when clinicians are more resilient, they are better able to attune to the needs of their patients and to provide more patient-centered, compassionate care [20].

The broad concept of resilience can be further tailored to the moral domain. Recently, the concept of moral resilience has emerged as a possible response to moral distress [21]. Moral resilience, or "the capacity of an individual to sustain or restore their integrity in response to moral complexity, confusion, distress, or setbacks" [22], might help clinicians to maintain their moral wholeness and continue to work in challenging circumstances even when the source of moral distress cannot be eradicated [23]. However, the association between moral distress and resilience is not well understood. In order to develop a robust scientific basis for moral resilience, it is necessary to define key concepts to test the hypothesis that moral resilience can reduce moral distress and other forms of moral suffering. Gaining a better understanding of the causal associations between moral resilience and moral distress is necessary to inform interventions to build moral resilience among PC clinicians and may result in increased well-being among PC clinicians and more engaged patient care.

Conclusion

PC clinicians have a moral imperative to care for others and to care for themselves [24]. There are currently many barriers to fulfilling these duties: systemically, the provision of high-quality PC is impeded by lack of training opportunities and lack of evidence-based outcomes data. On an individual level, PC clinicians may be plagued by moral distress that can lead to burnout, job dissatisfaction, or leaving the profession [25, 26]. In order to address these challenges, we offer two recommendations. First, PC programs that incorporate the core components of PC outlined in *Dying in America* should be implemented to ensure delivery of high-quality PC. PC research should also incorporate these core components so that results can be compared across studies. Furthermore, PC education components should be included in general education for all health care clinicians. Second, individual PC clinicians and health care organizations should invest in resources to mitigate the impact of moral distress and build ethical practice environments. More research is also needed to better understand moral resilience in the PC workforce. Enacting these recommendations holds promise for sustaining higher-quality and accessible PC and a more engaged PC workforce.

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