Prison life is difficult, and when a prisoner develops a serious illness, the difficulty is significantly compounded. The health care providers involved in the prisoners' care also face tremendous challenges in providing the best care possible while observing prison rules and the need for public safety, often in desperately underfunded, underresourced circumstances. This article includes a discussion of the ethical issues, especially justice issues, encountered in provision of care for prisoners that should, but often does not, approximate that of nonprisoner care. The history of the prison hospice movement is described. The case of a prisoner with extensive cancer and multiple symptoms is presented to highlight the ethical, existential, and practical issues encountered especially by the nurses, as well as other team members providing care for prisoners with advanced cancer. Then follows a discussion of the collaborative, compassionate approach to his care that maintained public and personal safety while optimizing symptom management and respect for his goals of care. Finally, suggestions for improving care of inmates with serious illness are provided.

KEY WORDS
bioethics, cancer, corrections, hospice, nursing, palliative care, prisoner

CASE OF MR A.C.

Mr A.C. is a 55-year-old man who presented with stage IV rectal cancer involving the rectum and regional lymph nodes. He is an inmate of a correctional facility and has a life sentence. He is separated from his wife and has 3 grown children. He previously worked at a dry cleaning company. His father has durable power of attorney for health care decisions and is very involved in his life. Mr A.C. presented to the surgical oncologist with symptoms of severe anorectal pain, difficulty passing bowel movements, bright red blood per rectum, and urinary retention. His pain was so profound that he did not eat for 4 days prior to the appointment, for fear of worsening his pain with a bowel movement.

Several weeks ensued between each referral appointment among various oncology and diagnostic specialties. Several weeks after his original presentation, he told the oncology team that he only wanted palliative, not curative, treatment, as he felt that "prison is worse than death." He purposefully missed some appointments, because he was too tired to endure the long, uncomfortable drive to the clinic from the prison, and the waits in the holding cell at the hospital between appointments.

From the first time he was evaluated by the oncology team, it took several weeks to get his pain under control. Each time a recommendation was made by the oncology team to the prison physician, it was followed, but it would sometimes take weeks between pain medication adjustments, because of the time that passed between appointments, which were the only times when medication adjustments were made. Overall it took 3 months and several changes in pain medication as well as palliative chemotherapy before his 9/10 pain score came down to what he felt was a tolerable 6/10. He also had significant blood and stool leakage, necessitating diapers. He was offered a diverting colostomy, which would likely help his pain, but he did not want it.

Throughout this time, A.C.’s father e-mailed the oncology team frequently. Because the families of inmates are not allowed to accompany them to the clinic, he requested clarification of test results and treatment plans, especially for pain management. The oncology team responded quickly to all of his father’s communications and tried its best to support him. They were frustrated that it was sometimes not possible to integrate best practices of palliative care, including family meetings, into the patient’s comprehensive cancer care.

The radiation oncology team offered treatments to consolidate the shrinkage that occurred with the palliative chemotherapy, noting to the patient that it could...
translate to prolonged survival. The patient declined that treatment, and in the course of a lengthy, heartfelt discussion with his primary physician at the prison, he decided on “do not resuscitate” status and ongoing treatment with palliative but not life-prolonging goals. At the last communication, 2 months prior to publication, Mr. A.C. remained on palliative care and continued to decline further cancer treatment.

HEALTH CARE FOR PRISONERS
Unlike other marginalized populations in the United States, prison inmates have a legally guaranteed right to health care. Prisoners comprise the only population in the United States that has a constitutional right to health care, protected by the Eighth Amendment’s clause barring cruel and unusual punishment. The basis for this is a 1976 Supreme Court decision, Estelle v. Gamble, which held that inmates must rely on prison officials for their medical needs, and therefore failure to respond to these needs may produce unnecessary suffering, torture, and/or a lingering death. The government is mandated to pay for prisoners’ health care, regardless of cost, because the prisoner can no longer obtain care independently. Louis Shicker, medical director of the Illinois Department of Corrections, writes, “Ethics and moral considerations dictate that because offenders are not free to care for themselves, society must provide humane care, which includes care of acute and chronic illness as well as relief of pain and symptoms.”

Legal scholar and prisoner advocate Gregory Dober writes, “While the law guarantees provision of care for prisoners, it frequently falls short of an acceptable standard of care. Unfortunately, in the United States, principles or standards for the care of prisoners are either undefined or vague. Rather than definitive doctrines, declarations, or a legislated definition of prison health care standards, providers in US prisons and jails rely predominately on case law for guidance regarding delivering minimal and/or adequate care. However, case law is used to generally determine violations of cruel and unusual punishment under the Eighth Amendment of the US Constitution.”

Unfortunately, there are multiple reports by inmates and their families, corrections officers, nurses, and other providers of neglect and even cruelty to prisoners with cancer. Patient and prisoner advocacy groups such as the Oncology Nursing Society, the Southern Poverty Law Center, and the American Civil Liberties Union make these reports available. They attest to routine delays in diagnosis and treatment of cancer, as well as neglect and denial of appropriate counseling, pain and symptom management, medical attention, and even provision of accommodations such as wheelchairs, prosthetic limbs, and even appropriate counseling and accommodations for blind patients. There has been more than 1 instance of a blind person signing a do-not-resuscitate order without knowing what they had signed. One prisoner was reported to discover that only because he was told it was the reason he could not have the cataract surgery he needed.

The Prison Legal News publishes court decisions and awards regarding egregious prisoner mistreatment and neglect. Many involve prisoners with cancer. For example, 1 such report described a prisoner with a severely painful, bleeding, rapidly growing penile lesion that was repeatedly ignored by prison medical officials for several months, until the lesion was so large it required amputation of the penis, and the patient then died after enduring a year of painful chemotherapy treatments. He had been seen multiple times by the prison providers whose treatment recommendations consisted of 7 pairs of clean shorts as the prisoner was bleeding profusely from the penile lesion. Multiple outside recommendations for biopsy were rejected as being too expensive and not urgent; the patient went for months without pain medication.

MORE ON DELAYED PRESENTATION OF CANCER BY PRISONERS
Patients who are incarcerated may sometimes arrive for an initial visit outside the prison oncology clinic with advanced stages of cancer and a history of prolonged signs and/or symptoms that would be unmistakable for cancer or another serious illness. In some cases, the inmate has voluntarily deferred health care. With a few exceptions, most prison inmates must pay for each visit to a health care provider, sometimes up to $5, and even if they are working, the wages are miniscule (in federal prisons, the rate is 25 cents per day), so they may want to spend the little money they make on shampoo or a candy bar rather than a visit to the health care provider.

Even when inmates such as Mr. A.C. present to providers with signs and symptoms of possible cancer, especially pain, they are not always adequately evaluated. There are various financial disincentives to perform diagnostic testing, and prison clinics or “sick call” is busy and full of patients with reports of pain and other symptoms so common as to be ignored or not taken seriously. But even when prison health care providers choose to evaluate a suspicious finding, it may take several weeks for the inmate to receive the attention of a specialist.

In cases of obviously delayed presentation of disease, our health care team members and others have described feelings of confusion and anxiety regarding disclosure of potential neglect and malpractice as well as advising legal counsel. They fear that they will exacerbate the patient’s emotional distress and frustration at the prison system, and neither are many incarcerated patients sophisticated, nor have families or other resources to obtain legal counsel. There is also uncertainty regarding
responsibility for disclosure and fear of retribution and that relationships with the prison medical personnel will be negatively affected and that could possibly affect their recommended treatment and symptom management of the current patients.

**DAILY CHALLENGES FOR PRISONERS WITH CANCER**

Inmates of correctional facilities face multiple challenges to conducting their daily lives. These include limited access to health care, poor diets, bad food, lack of communication, negative attitudes toward them from the public and from other inmates, toxic environment, restrictions on travel and outside communication, threats to their safety by predator inmates and others, constant noise and bright lights, minimal to no privacy, unexplained punishments, humiliating strip searches, endless loneliness, heartbreaking homesickness, and loss of control over even minor decisions.

When prison inmates develop advanced cancer, those challenges may be amplified by social abandonment, fear, anxiety, hopelessness, and other existential distress. Prison inmates generally have little access to a second medical opinion and limited opportunity to weigh their treatment options with health care professionals. Primarily because of fear of coercion, prisoners routinely do not have access to clinical trials. They have little recourse to challenge the care provided or to request alternatives.

**AUTONOMY AND DECISION MAKING**

Unlike care of nonincarcerated patients, where respect for autonomy is often at the ethical fore, public safety takes precedence over the care of the prisoner-patient. The normal ethos of privacy and confidentiality are waived. The need for multiple safeguards makes competent and compassionate provision of care challenging, from the time the patient leaves the corrections institution for the hospital and/or oncology clinic to the time of return—challenging, but not impossible. While the prisoner's autonomy is limited regarding freedom of movement and choice, he/she is free to make autonomous decisions regarding his/her medical care.

It is a common misconception that the warden or another prison official is the medical decision maker for the prisoner. As long as the prisoner has decision-making capacity, he/she is the medical decision maker and is also the person who designates his/her surrogate decision maker. In the case of Mr A.C., he freely refused further cancer-directed therapy and was also able to make a choice regarding code status. But at the same time, his decision making was limited as he did not have free access to health care providers and family meetings that often facilitate medical decision making and informed consent.

**PAIN AND SYMPTOM MANAGEMENT**

In the authors' experience, treatment with chemotherapy and/or radiation can be excessively burdensome for the inmate, because of inability to access management and advice with regard to the many symptoms and problems that can occur with these therapies once back in the confines of prison. Most inmates are not allowed to keep medications such as antiemetics in their cells, and if they are too sick to stand in the pill line, they miss their chance to obtain relief.

The idea of being unable to manage their symptoms can be deeply distressing to patients and, in Mr A.C.’s case, was a reason he considered not receiving cancer treatment at all.

It is also distressing for the treatment team to administer chemotherapy and/or radiation and hope that the adverse effects and toxicities will be adequately managed in the prison or jail. That includes the risk of neutropenic fever, which if left untreated can be fatal. The oncology team relied on frequent communication by phone, e-mail, and written documents to educate and remind the prison personnel about the emergent aspects of recognition and treatment of neutropenic fever and other serious toxicities.

Pain management is perhaps the most difficult of all clinical issues for prisoners and providers alike. In many instances, even if a pain management plan is developed and communicated to the prison, it is not always precisely followed, as prison physicians and nurses vary significantly in their knowledge and comfort level with pain and palliative therapy. A study of inmates with cancer pain and providers in a Texas prison system indicated significant undertreatment of cancer pain. The study described the most common barriers to cancer pain treatment as provider concerns about drug misuse and diversion, concerns about patient credibility, inadequate assessment of pain and pain relief, and excessive institutional regulation of prescribing analgesics.

Facilities that can give opioids in the general medication line or “pill line” cannot provide certain medications, such as analgesic tablets, for fear of prisoners “pocketing” the pills in the buccal mucosa or elsewhere. The pill line is only 3 or 4 times per day, with the last one being at 7 or 8 PM, making the nights very long for patients who have pain and are not prescribed long-acting analgesics. There are delays because of opioids not being on formulary. A discussion with the treating physician is often required to establish or escalate opioid dosing to achieve adequate pain control.

Often the infirmary, a hospital unit within the walls of the prison, is the only place that patients can receive opioids, especially but not limited to parenteral opioids. If they are housed in the prison infirmary, they may have a better chance for symptom control, and nurses may have a greater influence on their symptom management. However, many inmates resist transfer to the infirmary because they are then unable to visit the canteen to buy preferred food, and they do not have access to their friends and acquaintances in the general population.
TRAVEL AND TRANSPORT AS A BARRIER TO DIAGNOSIS AND TREATMENT

Prisoners with outpatient appointments are most often transported in groups, which requires they rise and leave for the hospital or clinic very early, and so they often miss their morning medications, including pain medications. Along with worsening pain, they may experience withdrawal symptoms unless they are provided their opioids at the clinic, which is not expected standard of care. The patient must request pain medication and risk being considered a “drug seeker.”

Travel to and from the prison can be long and uncomfortable. The inmate is shackled and unable to move around. Consider having bone pain from metastases, nausea from chemotherapy or cancer, or, as in the case of Mr A.C., pain in the anal region from tumor invasion. Bouncing around on a hard bench for minutes to hours can be nearly impossible to endure, no matter how much the inmate wants treatment or to see the provider.

Once the inmate has seen the provider, he/she will have to wait in a holding cell, often for several hours, until all the other inmates are seen, before the van returns to the prison. The nurses try to replace missed medications but can do little more to ease the discomfort of the interminable waits. While at the hospital, inmates endure the stares of other patients, visitors, and hospital personnel, as they are transported by officers in their regulation uniforms, shackled in handcuffs and ankle chains, to various clinics and diagnostic procedures.

Mr A.C. simply could not endure the prospect of frequent travel for the visits proposed by the radiation and medical oncologists, despite the possibility of long-term remission. It was too painful for him to travel daily under the previously mentioned conditions, and there were no viable alternatives because of financial, staffing, and security issues at the corrections level.

EXISTENTIAL CONCERNS OF PATIENTS AND PROVIDERS

As previously discussed, many prisoners experience feelings of isolation, loss, grief, despair, hopelessness, homesickness, depression, and sadness, all of which may be compounded by the diagnosis of a lethal cancer and the symptoms produced by treatment and the cancer itself.

As the prisoner becomes more aware of his/her mortality, his/her circumstances with regard to freedom of movement and communication may render the spiritual and relational work of dying profoundly challenging. Achieving the intimacy and privacy to be able to say Ira Byock’s “4 things”: Please forgive me, I forgive you, thank you, I love you,” is challenging outside prison walls and often much more so from within.

The experience of those caring for the patient may be one of shared despair and sadness, as well as frustration with difficulty providing and achieving symptom management, infrequent and irregular clinic visits, and loss of control over the timing and duration of those visits. In the case of Mr A.C., even when the nurses established a relationship with the patient that they felt was therapeutic, scheduled visits were interrupted or did not occur at all.

Nurses and other health care providers who work with sick prison inmates encounter multiple ethical and systemic issues affecting patient care. The prison infirmary and cancer clinics are unique environments where public safety always and highly visibly takes significant priority over inmate health and safety. Nurses and other health care providers may find their personal and professional ethics challenged and experience significant moral distress, as members of our team did. They also must confront their own feelings, biases, ambivalence, and ideas about caring for criminals, especially those who have committed violent crimes. In the prison setting, access to others with special skills in assisting with existential concerns, such as chaplains, psychologists, counselors, and social workers, is variable and dependent on the culture of the prison, established programs, and funding. In some institutions, the prisoner-patient must meet criteria for hospice care before he/she is eligible to receive those services. Funding for these services is often stretched tight across the institution, and often there is not enough time for chaplains and others to do more than offer a prayer or 15 minutes of conversation (per personal experience and communication with other members of the prison health care teams).

In Mr A.C.’s case, the existential burden extended to his family. In many instances, families of prisoners bear significant burdens similar to those of the prisoners themselves—missing the person, feeling helpless, and unable to communicate privately for extended periods, especially when the prisoner requests help with decision making. The family cannot attend clinic visits with the patient. In addition, the family is often helpless in the face of the prison system with respect to helping their sick and dying family member achieve pain and symptom management and meet their goals of comfort and closure at the end of life.

In the case of Mr A.C., the patient’s father acted as his advocate and communicated often by e-mail and phone. As members of the oncology team became familiar with him, it became clear that he was grieving for his son, not only for his cancer, but also for the life sentence he was serving. As communication was always by e-mail or telephone, it was more challenging to console him, to gauge his feelings, and to provide support. The oncology team made sure his e-mails were answered promptly and that each concern was addressed.

One of the oncology team said, “His Dad expressed different goals from his son. His father’s perspective was that...
he did not want him to suffer, but he also wanted him to take all the treatment available to him. I see this among many patients, not only incarcerated ones, when it comes to those they love. The one difference is that often the communication between incarcerated patients and their family members is fragmented. Family members cannot join incarcerated patients for visits to discuss plans and goals of care. What Mr A.C. may say to his father once he is back at the facility may differ greatly from what he has discussed with us. It was difficult from a nursing standpoint, understanding the father’s internal struggles, but also trying to carry out Mr A.C.’s wishes based on his situation and discussion between him and his Dad” (personal communication).

Medical clemency is frequently hoped for, but is not often possible until the very end of the patient’s life, if at all. Each state has its own board and rules with regard to clemency. In the authors’ experience, each inmate was reviewed with consideration of his/her previous crimes and life expectancy. Inmates with life sentences are rarely released. Those who have no families and nowhere to go are rarely released. In any case, the oncology team encourages the families of the inmates to apply, in the outside chance they may go free, even on their last day of life. The authors have each heard many an inmate state his/her greatest wish is to die free of shackles.

In many cases, inmates are homeless and without families when they are incarcerated, and the other inmates and prison personnel become the closest family they have. The creation of hospice programs involving other inmates as volunteers has been one of the most successful, and the philosophy of forgiveness and redemption runs deeply through descriptions of those programs.

LESSONS LEARNED FROM OUR EXPERIENCE AS PROVIDERS FOR PRISONERS WITH CANCER

The following are several important lessons we learned about the provision of care to our incarcerated patients with advanced cancer:

1. Appropriate Cancer Care. It is clear that advocating for justice for these most vulnerable of patients means to focus on approximating their treatment as closely as possible to that of nonincarcerated patients with advanced cancer. The first step is to make sure the patient’s cancer is diagnosed and treated appropriately. In most hospitals and medical centers, tumor boards and specialty multidisciplinary conferences are held to review patient case to develop a treatment plan that will best serve the patient’s goals. Prisoners’ cancer care should approximate that of the nonprisoner. Leveling the playing field in any way possible while still respecting and abiding by the department of corrections is key to advocating for justice for prisoners.

In the same vein, the patients should have the benefit of the same cancer support team that works with the nonincarcerated patients. That includes, if at all possible, chaplain and other spiritual support services, counseling, physical and occupational therapy, wound care and other specialized nurses, and pharmacy professionals.

2. Communication. There are 2 major venues of care for the patients: the care they receive in the oncology clinics and the care they receive in the prison. Continuity of care and communication between these 2 sites of care are essential. In Mr A.C.’s situation, once a regular treatment team was in place at the oncology clinic, and relationships were forged between the nurses and the prison providers, recommendations for pain and symptom management were followed more closely, and the patient achieved better pain control in a more timely fashion. Communication also increased the likelihood of patients arriving at appointments and receiving more timely care, thus reducing delays in care due to misunderstandings by the patient and facility staff.

The 2 groups also shared knowledge regarding specific cancer treatment and supportive care. Continuing on the momentum of the success of those relationships, an inaugural hospice and palliative care conference for local correctional centers brought together prison medical professionals with their counterparts from the medical centers serving the prisons. The conference provided pain and symptom management education as well as a chance to meet and develop or seal relationships that had been forged several years prior. The hidden agenda was perhaps nurturing of a more open, compassionate, and proactive approach to such patients with multiple symptoms and existential issues. It seemed that it was after that conference when our oncology patients began regularly receiving recommended doses of opioids and other medications for palliation. There was a significant uptick of telephone calls from both provider teams, and it appeared to the oncology providers that the patients had better pain and symptom control overall.

3. Respect for Autonomy. Despite the fact that the patient is incarcerated, he/she still has full rights to make health care decisions. Respecting his/her right to make decisions and providing appropriate information regarding diagnosis, prognosis, and treatment to aid in decisions are imperative and extend dignity and compassion to the person. Kindness, patience, courtesy (in our clinic, the patients are called “ma’am” and “sir,” not “offender X”), and a listening ear are acts of humanity that each patient deserves, no matter what their station in life. Such an approach may influence how others treat the patient. Extending those same courtesies to the patient’s loved ones is also important and conveys compassion and respect for dignity. Those acts of human compassion and respect also help to build trust.
between the patient, his/her family, and the combined treatment team at the clinic and the prison facility.

4. **Strict Confidentiality and Privacy.** These are not always realistic in the corrections setting, but one should limit to as few as possible the people present when sensitive matters are discussed and try to include only those necessary for safety and patient care. In the authors’ experience, there have been times when the prisoner especially did not want his/her human immunodeficiency virus diagnosis discussed in the presence of the officers, as there are certain stigma attached in various prison venues.

5. **Dietary Considerations.** Nutrition is an important symbol of care and nurturing. Furthermore, catabolic states and weight loss are often documented in patients with advanced cancer and especially those undergoing chemotherapy. It is helpful to discuss the patient’s nutritional needs and wishes, as well as with corrections personnel who are the most knowledgeable regarding what foods are available to certain patients.

6. **Supportive Care.** A system-wide palliative and hospice approach has been shown to be helpful to patients with limited prognosis and need for supportive care in the medical, spiritual, emotional, and psychological realms. Adoption and incorporation of national palliative care guidelines into routine care of all seriously ill patients are desirable.

**SUMMARY**

Caring for patients who are inmates of correctional facilities is challenging. But as with all patients, the best approach is to meet them where they live. All patients present with a variety of challenges to the caregiver, but we must always remember that those challenges are minor compared with those confronting the patient. Justice for these most vulnerable of patients is foremost, and we must strive to work within rules and boundaries to respect the patient’s autonomy and provide compassionate, respectful, and competent care with the goals of quality of life and relief of suffering.

**References**