

## CASE REPORT

# Respecting Autonomy and Promoting the Patient's Good in the Setting of Serious Terminal and Concurrent Mental Illness

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**Background:** Clinicians at the bedside regularly encounter surprises or unexpected clinical developments that carry emotional, social, or moral overtones—especially when death is anticipated or when patients are particularly vulnerable. In such circumstances, clinicians may struggle to find practical clarity in making treatment plans that honor their fiduciary (literally, “entrusted”) duty to uphold equitably the ethical principles of beneficence, nonmaleficence, patient autonomy, and justice. **Methods:** We present the case of a patient who appeared to be actively dying and received an indwelling urinary catheter for the purpose of ensuring comfort. However, it led to an unintended reversal of renal failure and exacerbation of underlying psychiatric disease. This led to a meaningful change in the patient’s prognosis. It also created pragmatic challenges to shared decision making, which required an intentional interdisciplinary approach to balancing beneficence and patient autonomy. **Conclusion:** Palliative Care offers a holistic clinical approach to complex suffering. Palliative care specialists develop advanced skill sets in prognosis estimation, nuanced communication issues, and patient-centered goal setting. As this case highlights, prognosis can shift dramatically in the perimortem period, even with small changes in care plans. This case presented several biomedical, social-cultural, and ethical challenges to the team. Lessons from the case are presented regarding: the role a specialist palliative team might play throughout all stages of serious illness; approaching prognostication as an iterative rather than solitary task; and utilizing an ethical framework to care planning when there are barriers to shared decision making.

## INTRODUCTION

As death approaches, patients and clinicians alike often face complexity, uncertainty, and moral distress—especially in the wake of unexpected clinical developments. Patients who are critically ill are inherently vulnerable to the physician’s power to potentially “help” or “harm” [1], and this vulnerability is heightened in states of inability

to organize thoughts or communicate clear wishes. Physicians and other healthcare clinicians have a fiduciary or entrusted obligation both to promote care that is in the patient’s best interest and also to respect their autonomy – and to uphold the patient’s inherent “humanity, dignity, and worth” [1].

Palliative care specialists are uniquely trained to manage complexities in ethical, biomedical, social-cultural

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†Abbreviations: HPM, Hospice and Palliative Medicine; EPA, entrustable professional activity; PPS, Palliative Performance Scale.

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tural, and emotional-spiritual domains. While they are experts in managing uncertainty in these areas, there are times when the clinical picture presents a true dilemma. To this end, we describe the aftermath of an unusual and unintended therapeutic development from a comfort-focused intervention performed very commonly at end of life: namely, placement of an indwelling urinary catheter [2].

The patient in question appeared to be dying of renal failure, but due to some evidence of urinary retention, a catheter was placed with the intent of promoting comfort at end of life. Two unintentional consequences ensued. First, the patient's level of alertness improved, possibly because the catheter reversed one of the underlying causes of his renal failure. This renewed alertness led to the second consequence – worsening psychosis from the patient's underlying and untreated paranoid schizophrenia. Although intended to palliate symptoms, the indwelling catheter unintentionally treated one disease process and unroofed another. This caused a substantial shift in prognosis and medical management. Accommodating this new information into patient-centered goals discussions was challenging due to the patient's psychiatric pathology. This patient's case illustrates the role that palliative clinicians play in managing complex suffering, estimating and communicating prognosis, and coordinating complex care. The case also highlights how palliative care can approach the challenges of 1) attending to both a biomedical disease process and a patient's whole personhood, and 2) navigating challenges between respecting patient autonomy and the physician's obligation to beneficence.

## CASE PRESENTATION

A 68-year-old veteran presented alone to an emergency department reporting a history of "cancer," a lack of energy, and a persistent sense that his death was near. Laboratory evaluation revealed severe metabolic derangements consistent with acute renal failure with potassium 8.4 mEq/L (normal range 3.1-5.1), serum bicarbonate 9 mEq/L (normal range 22-32), blood urea nitrogen 246 mg/dL (normal range 5-22), and serum creatinine 38.4 mg/dL (normal range 0.4-1.2). The patient was not able to provide more details regarding his medical history and no family or next of kin were identified or available.

The patient voiced that he understood that his kidneys were shutting down; he indicated that he had heard this message before. He expressed to the hospital's staff that he did not wish to pursue any further painful procedures (including basic blood draws for laboratory) but rather voiced a desire to "just keep [him] comfortable." The clinical team supported this decision and an end-of-life care plan was arranged to focus on comfort, as death was expected to occur relatively quickly given the sever-

ity of his acid-base and metabolic conditions. The patient stated he did not want repeated injections or blood work; however, he agreed to placement of an indwelling urinary catheter and peripheral intravenous line. He was admitted to the inpatient palliative unit for anticipated end-of-life care.

The patient's clinical picture changed dramatically over the next few days. His somnolence gave way to insomnia, echolalia, and lack of inhibitions. He voiced multiple delusions of paranoia, religiosity, and persecution. His oral intake increased dramatically and he developed polyuria; however, he refused further blood draws to recheck his serum chemistries.

The patient's verbal perseveration on rectal and pelvic issues prompted an evaluation for constipation, which was negative. However, a regional search for medical records revealed diagnoses of long-standing paranoid schizophrenia as well as recent computed tomography scan of the pelvis showing a bulky mass with malignant features near the prostate. He had been lost to follow up, and no biopsies or interventions had occurred.

A new working diagnosis emerged: that the patient's paranoid schizophrenia had been dampened by the somnolence which was the clinical manifestation of his post-obstructive renal failure from his presumed prostate cancer. Upon further review of available records, it was noted that the patient had consistently refused to take antipsychotic treatments; no court order for involuntary treatment of his mental health condition was in place.

After a week of hospitalization, the patient was refusing basic nursing cares including allowing for vital signs to be obtained. Repeatedly, the patient attempted to enter other patient rooms and demonstrated disruptive behaviors in the unit (including swinging his urinary catheter bag at nursing staff). He voiced a persistent desire to not receive any psychotropic drugs.

The palliative team believed that patient lacked decisional capacity but acquiesced to the patient's request for second opinions with both psychiatry and internal medicine. At that time, both services concurred that the patient lacked decision-making capacity regarding an appropriate understanding of his overall medical condition. However, there was less clarity about whether the situation warranted involuntary psychiatric treatment. Was this patient an imminent risk to himself, such that performing diagnostic testing against his stated wishes would directly alter the medical care plan? At the same time, more extensive searching yielded no family or surrogate identification.

The Ethics Consultation Service was consulted to help guide decision making. It now appeared that the patient was not imminently dying; in fact, he was functionally independent with activities of daily living including eating, dressing, and walking. The patient voiced an

interest in rehabilitation but declined the requisite repeat laboratory evaluation, citing beliefs that this “would anger God.” As not mandated for imminent safety or changes in medical management, no further bloodwork or diagnostic workup was obtained involuntarily.

The patient’s most significant medical condition was now psychosis, and this did not appear attributable to acute renal failure, but rather his underlying mental health condition. On one occasion, the patient threatened to elope from the facility. In this instance, there appeared to be a more imminent risk both to self and to the physical safety of both staff and other patients. After discussion with Ethics and psychiatry, one dose of the neuroleptic haloperidol was administered. However, no further diagnostic workup was done without more explicit consent. Since a court order is needed for ongoing involuntary psychotropics, this plan was considered on multiple occasions. For the most part, skilled nonpharmacologic interventions and an intense interdisciplinary approach to his care was adequate in calming the more disruptive symptoms of psychosis.

Slowly over the course of several weeks, the patient’s psychosis became less intrusive and he intermittently agreed to psychotropic medications. He was able to participate in conversations about his presumed prostate cancer and expressed wish to defer further disease directed evaluations or treatments. Notably, he was able to voice understanding that deferring treatments may well shorten his life expectancy. He was transferred from the Palliative Care to the internal medicine primary service.

By that time, he was able to demonstrate enough capacity to determine disposition. Despite the clinical teams’ perspective that increased social support services and regular medical care would be in his best interest, he was consistent in his response that such a care plan was at odds with how he wanted to live. Specifically, he cited the core values of being alone and capable of travel. He argued that establishing care in a city would not allow him to live as he wished. He declined offers for a string of referrals to nearby cities. Importantly, his capacity assessment established that he understood the consequences of the choices, and there was no clear and imminent risk of harm to self or others.

The multidisciplinary team included mental health providers and a board of mental health hold was discussed at length. However, the patient consistently demonstrated capacity and voiced unequivocal values to live as he always had. Ultimately, the teams determined that there was not sufficient medical justification to hold the patient against his wishes. He was discharged at his request to self-care with a urinary catheter in place, having declined offers for referrals to hospice, ongoing nursing care, and other social support services.

Within a few weeks, the patient was found dead in

his vehicle where he had wanted to live, without evidence of foul play, but also without follow up that was encouraged but not pursued by the patient.

The patient ultimately made choices that were consistent, ethically permissible, and very much in line with his own value systems. The values the medical team held (namely, therapeutic stability, secured access to social supports, mitigation of risk factors, and preventative medicine) conflicted with the values the patient held (absolute self-reliance and bodily autonomy).

Despite the anticipation by most clinicians that this discharge plan was far from the “safest” option offered, it was in line with his values and he clearly understood the issues at hand. Preventing him from pursuing the discharge plan of his choice would not have been ethically permissible.

## DISCUSSION

Palliative care is an approach that focuses on comprehensive symptom management, alignment of complex treatment plans with person- and family-centered goals, and interdisciplinary care coordination [3]. It attends not only to biomedical disease processes, but to psycho-emotional, social-cultural, practical, and spiritual contexts of illness experiences [4]. This case illustrates several important aspects of palliative care in practice in the setting of complex somatic and mental illness. Furthermore, it illustrates several common challenges for a palliative clinician:

1. Creating a clinical picture that includes but does not exclusively rely on biomedical information, and attending to suffering across multiple domains throughout all stages of the patient’s lived experience with serious illness;
2. Synthesizing emerging clinical information into a prognosis not once, but iteratively as the patient’s clinical course unfolds; and
3. Utilizing an ethical framework to care planning when there are barriers to shared decision making.

*Specialty level palliative care is appropriate for complex suffering throughout any stage of serious illness.*

Although commonly misconstrued as care provided exclusively at the end of life, palliative care is appropriate throughout all stages of serious illness—regardless of setting, stage of illness, or expected prognosis [4]. In this case, the patient had life limiting illness at every stage of his hospitalization; initially renal failure with functional and physical needs, and later on psychoemotional and spiritual needs in the context of his cancer and schizophrenia. Palliative care’s interdisciplinary approach included nurses, physicians, social workers, and chaplains,

all of whom attended to the patient's multiple domains of suffering in unique ways.

Palliative care also emphasizes *relationships* rather than *tasks* as "the central feature of health care" [5]. As the care relationships between this patient and the palliative clinicians evolved, each member on the team remained relevant and integral to his care, even when not at end of life. By aligning with the patient's goals, preferences and values, and seeking a constructive therapeutic relationship as a "central goal" [6], the palliative care team honored the patient's personhood and provided him with recommendations built more on respectful, humble care than on legalism and self-interest.

***Specialty palliative clinicians intensively develop skill sets in estimating and communicating both prognosis and uncertainty thereof.***

This patient's case illustrates the complexity of a skill integral to the practice of a Hospice and Palliative Medicine (HPM) clinician: prognostication. This skill generally receives much less attention in the medical literature than either diagnosis-making or treatment planning [7]. Many prognostication tools are in various stages of development and validation, but it is far from clear to what extent these tools are currently used in medical decision making or patient-clinician communication [8].

Specialist HPM clinicians develop prognoses based on both population-level evidence and individual-patient factors. This skill is considered a core competency and entrustable professional activity (EPA) of the specialty, and encompasses both estimation and effective communication [9]. This process involves synthesizing epidemiological and pathological findings together with individual clinical factors [7,10].

In this case, the patient was initially thought to be in his last days of life, based on critically abnormal chemistry evaluation consistent with advanced acute renal failure and a low Palliative Performance Scale (PPS) showing decreased alertness, minimal activity and oral intake, and dependence in activities of daily living. Days later, several clinical variables had changed, and so had the prognosis – illustrating that it is not enough simply to develop a prognostic "pronouncement" once and move on. Rather, clinicians must revisit and adjust a patient's prognostic estimate iteratively as the clinical condition changes.

Prognostication is fraught with subtlety, complexity and bias, and prognostic discordance and over optimism – each are well described phenomena [11,12]. Especially for adults and children with rare or unique constellations of medical conditions, developing a prognosis depends on information from many sources, including the caregivers [13]. Prognostication is most meaningful when a robust interdisciplinary team can continuously discuss and share

expertise. Palliative care specialists seek insights from many perspectives to help hone and adjust prognosis.

***Palliative Care specialists can enhance truth telling, sense making, and shared decision making in complex illness, especially when there are barriers to ideal patient or surrogate participation.***

Effective communication of prognosis involves both engaging in dialogue with other medical teams involved and eliciting from patients and families how they wish to receive prognostic information. Sharing prognostic information should offer clarity between what is known and what is uncertain and should be done in ways that are developmentally, culturally, and contextually appropriate for patients and their families [4].

In this case, the patient consistently declined scans, chemistry evaluations, and details about prognosis, but still needed some context upon which to base his medical decisions. At each point, he and the clinician teams were able to together construct a succinct and meaningful shared understanding of "what to expect," while avoiding a level of detail that the patient would have found offensive or distressing.

Modern clinical bioethics supports honoring a patient's wish for less information and not "thrusting truth" upon them as a necessary component of respecting patient autonomy with appropriate cultural humility [14]. Several proposed frameworks are available for helping clinicians approach shared prognostic awareness even early in illness arcs [15].

***"Dying," though consistently underdiagnosed in the era of advanced medical technologies, does not diminish the importance of clarifying diagnoses, honing prognoses, and adjusting care plans.***

In an era of multimorbidity, advanced chronic illness and evolving life support technologies, the diagnosis of "dying" has become less straightforward [16]. Once medical teams, patients, and families have come to a common understanding that death is near, there is an all-too-prevalent misconception that care is "withdrawn" by stopping life sustaining technology. In truth, perimortem care is rarely that simple or easy to predict, and care is never withdrawn. End-of-life care needs are dynamic, holistic, and person-centered – and patients' physiologic responses to these changes in care plan are sometimes just as dynamic. In this case, the "small intervention" was a catheter placement, but many types of treatment changes near end of life might offer similar dramatic changes.

One such common example is the dynamic role between oral intake, nutrition, and fluid status. In earlier stages of a patient's illness, nutrition might be examined carefully with the goals of restoring vitality. Over time,

the “goals” of oral intake might shift from restoring *objective measures of vitality* to enhancing *subjective quality of life* [17]. Then, as patients enter the dying process, oral intake typically declines – but so do iatrogenic fluids and metabolic needs. Daily fluid balances in the weeks before death tend to be negative but correlate poorly with directly observed symptoms of dyspnea or terminal secretions [18], possibly due to the wide variance in hemodynamics, fluid reserves, positioning, and metabolic demand. It is possible that even inefficient circulatory systems, when relieved of ongoing intake, are able to redistribute some fluid and thus improve edema, secretions, and breathing effort [19,20]. When small changes have substantial impacts on symptoms, reframing what the “right amount” of fluid and nutrition is in a dying person’s care is an essential part of daily rounds for the palliative care specialist.

Transitioning from life-sustaining treatments (focused on strength, homeostasis, and function) to aggressive symptom management and holistic care (focused on the present experience, relationships, life completion, and well-being) represents a substantial paradigm shift for patients and their families. Even the prospect of loosening a long standing regimen of glycemic control can be stressful [21]. Normalizing and explaining the changes seen in dying is a crucial part of ensuring that patients and families do not misinterpret new phenomena as distressing symptoms [17].

Near end of life, human physiology and the resulting symptomatic manifestations change in complex and interrelated ways. This dynamic physiology highlights the need for an iterative, cyclical approach to symptom assessment, treatment, and prognostication.

## CONCLUSION

All clinicians strive to uphold their duty to be worthy of the trust of their patients. Often, this requires clinicians to weigh their actions in the light of the principles of beneficence, patient autonomy, nonmaleficence, and justice. This case describes a scenario where, due to an unexpected prognostic shift following a routine intervention, the patient’s ability to participate in shared decision making was challenged by the escalation of underlying psychotic symptoms. This case highlighted the tension that can emerge between beneficence and autonomy. It illustrated how care must be “more than solving difficult diagnostic, therapeutic, or ethical dilemmas” [1] – care must involve a true relationship that involves meeting and listening to patients on their own terms. When barriers exist to robust shared decision making, a broad interdisciplinary team – including palliative care specialists – is essential for managing suffering, addressing uncertainty, and allowing abstract theories to flourish into actual relational, patient centered care.

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