

## A Case of Mistaken Capacity: Why A Thorough Psychosocial History Can Improve Care.

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Patrick Romano, MD, MPH; Debra Bakerjian, PhD, APRN, RN; Katrina Pasao, MD; Pouria Kashkouli, MD, MS; and Amy Nichols, RN, EdD, CNS for this Spotlight Case and Commentary have disclosed no relevant financial relationships with commercial interests related to this CME activity.

### Learning Objectives

- Describe the four elements that healthcare providers should use to assess capacity
- Summarize the importance of including psychosocial history as part of the patient’s complete history
- Describe the strategies to strengthen psychosocial training for medical and nursing trainees
- Articulate the importance of early referral to palliative care
- Recognize implicit bias when caring for patients with substance abuse or socially disadvantaged individuals

### The Case

*A 72-year-old man with history of chronic obstructive pulmonary disease (COPD), tobacco and alcohol use disorder, and metastatic prostate cancer (not currently on therapy) was brought into the Emergency Department (ED) by his daughter from his board and care facility with weight loss and worsening pain. The patient was hypotensive on arrival, but his blood pressure improved with fluid resuscitation. He was cachectic with a body mass index (BMI) of 12.6. Laboratory tests were notable for acute kidney injury, metabolic acidosis, hypomagnesemia, hypophosphatemia, hypocalcemia, hypoalbuminemia, and pancytopenia. Chest imaging was unremarkable. Computed tomography (CT) of the abdomen/pelvis showed an enlarging prostate mass with invasion into the posterior bladder wall and worsening nodal and bony metastases. Urinalysis revealed large leukocyte esterase and many white blood cells.*

*The patient was given intravenous fluids with electrolytes and started on antibiotics for a presumed urinary infection. Preliminary chart review revealed multiple missed oncology appointments. The patient was a poor historian; he was alert and oriented to person and place but could not recall his prostate cancer diagnosis and was unaware that he was supposed to follow up with oncology. According to the patient's daughter, he had been living at the board and care facility for several months. She had not seen him since he was admitted, and she found him covered in urine and malnourished. She knew of his cancer diagnosis but was unsure why he was not receiving treatment. The palliative care service was consulted to clarify goals of care.*

*Further medical record review revealed that the patient was incidentally diagnosed with prostate cancer, metastatic to bone, when he was admitted for a fall related to alcohol use six years earlier. He was seen in clinic one month after that discharge, without family present, and scheduled for outpatient biopsy. The patient showed up for his biopsy without adequate preparation and so it was rescheduled. He did not show up to the following four oncology appointments. His daughter was notified by phone, the patient re-established care in February of the following year, underwent biopsy in May, and started on androgen deprivation therapy in June. However, he continued to miss scheduled appointments. He presented to clinic in December with his nephew to re-engage with therapy; however, he missed his appointment in infusion clinic. His nephew called one year later to reschedule but the patient only received two doses of androgen deprivation therapy, with no further documentation in the electronic health record until he was readmitted one year before the current admission. During this prior admission, the Palliative Care team called the patient's daughter to obtain collateral information. According to the daughter, the patient had developmental delay and been conserved by his mother until she passed away a decade earlier. The daughter also reported that her family had difficulty locating the patient due to his history of alcohol abuse and marginal housing. On interview, it was determined that the patient did not have capacity to make complex medical decisions. He was discharged to a skilled nursing facility, and then to a board and care facility when he failed to improve. He missed two more oncology appointments before his current admission with cancer-related pain.*

*Based on the patient's poor functional status (Eastern Cooperative Oncology Group Performance Status 4), he was not considered a candidate for additional therapy. After a discussion of goals of care with the patient and daughter, he was enrolled in hospice.*

## **The Commentary**

## **Assessing Mental Capacity**

Impaired mental capacity is fairly common in hospitalized patients. A study in King's College Hospital found 31% of patients were determined to lack mental capacity, and similar studies in general hospitals have found 9-52% of patients lacked mental capacity.<sup>1</sup> Thus, it is important for clinicians to routinely assess capacity. Capacity is defined as a person's ability to make an informed decision about medical treatments and other aspects of care.<sup>1</sup> Medical decision-making is the ability of a patient to understand the benefits and risks of, and the alternatives to, a proposed treatment or intervention (including no treatment).<sup>2</sup> Capacity is often mistaken as competency, which is a legal determination by a judge regarding whether a person lacks decision-making skills in relation to finances, property, or other legal matters or proceedings. The definition of capacity is that patients have decision-making capacity if they can demonstrate the ability to comprehend the information presented, understand the risks, benefits, and consequences of their decisions, communicate a decision consistently, and explain their reasoning behind their decision.<sup>2</sup> Capacity is often assessed intuitively and can be fairly apparent; however, there are instances that may not be as obvious. Capacity can be affected by many factors including dementia, delirium, learning disability, or psychiatric disorders, which may present atypically or in a milder pattern. Other issues may include impaired understanding of the situation due to young or old age, limited educational attainment, or significant cultural or language barriers.<sup>3</sup>

In England and Wales, the Mental Capacity Act (MCA) 2005 provides a helpful framework that healthcare professionals from other countries may choose to follow. The purpose of this act is to protect patients with impaired decision-making capacity. The MCA includes the following five principles:

1. There should be a presumption in favor of decision-making capacity for all patients.
2. Take all reasonable steps to maximize ability before determining that a patient lacks capacity.
3. A person does not lack capacity merely because they make an unwise decision.
4. Where a patient lacks capacity, any decisions taken on their behalf must be in their best interests.
5. A best interest decision must be made in a way that is least restrictive on that individual.<sup>4</sup>

The presumption that all patients have decision-making capacity empowers decisions made by the patient and, in effect, protects persons at risk for stigmatization. Persons at risk often include the elderly, those who have a history of substance abuse, or those with mental health conditions. Healthcare team members may incorrectly assume that these patients are unable to make decisions for themselves. It may also be incorrectly assumed that these patients have a poor support system or have poor motivation to pursue care.

A more formal, structured, and routine evaluation should take place to prevent losing these patients to follow-up. Routine evaluations in both inpatient and outpatient settings are important to gather a sense of the patient's baseline. The provider must assess capacity with a directed interview to determine the four elements of capacity:<sup>2</sup>

1. Understanding: The ability to state the meaning of the relevant information
2. Expressing a choice: The ability to state a decision

3. Appreciation: The ability to explain how the information applies to one's situation
4. Reasoning: The ability to compare and infer consequences of choices.<sup>5</sup>

The first course of action is to define the decision that the patient has to make and identify the consequences for each possible choice. The patient must be given all the information needed to make an informed decision, including alternatives to a proposed treatment. Interpreters should be used to prevent any language barrier. It is important to remember that patients do not need to make the "correct choice"; however, they do need to have adequate rationale behind their decision. If there is no clear determination of capacity, formal assessment tools may be used. Additional structured assessment tools that can be used include the [Aid to Capacity Evaluation](#) (ACE), the [Hopkins Competency Assessment Test](#), Understanding Treatment Disclosure, and the [MacArthur Competence Assessment Tool for Treatment](#).

In most cases, patients have the capability to make well-informed decisions surrounding their treatment plan, however, there are cases in which decision-making capacity may change due to fluctuating mentation. In other cases, it may seem that a patient has capacity when they, in fact, do not. Capacity reflects a spectrum of decision-making ability: adequate, marginal, or inadequate. In this particular case, the patient exhibited knowledge of his cancer diagnosis and expressed interest in pursuing treatment, initially determined as adequate capacity. However, the patient was lost to follow-up several times. It was later confirmed that the patient did not have full understanding of his situation and could not offer a rationale for his decisions, likely secondary to his childhood diagnosis of developmental delay. In cases in which capacity is questionable, the provider must enlist the aid of a consultant with expertise in determining capacity.

It is crucial to identify whether the patient has any disorders that may interfere with their decision-making skills.<sup>1</sup> The patient may be unaware of these barriers. In patients with schizophrenia, patients often have poverty of speech and thought that prevent them from organizing thoughts. Patients with delusions may believe a doctor is trying to harm the patient instead. Those with learning disabilities may not be able to logically piece together information to form a decision. It is also important that patients are given the chance to name a proxy decision maker to make decisions in their best interest in the event that they are not able to participate in informed decision making. The proxy decision maker must determine the decision that is more consistent with the patient's actual wishes and also serves the patient's best interests.

System barriers that must be overcome to appropriately address the question of mental capacity include the lack of multidisciplinary teams involved in a patient's care. For example, teams that do not include a social worker or mental health professional may not have the resources to identify and mitigate psychosocial issues that affect one's mental capacity. Frequent discussions between patients, families, and healthcare teams are essential to determine what decisions may align with both the patient's best interest as well as their personal values. Providers have a responsibility to ensure that they have taken all the steps necessary to help a patient make decisions for themselves before reaching the conclusion that the patient does not have capacity.

### **Psychosocial History: Getting to Know the Person Within the Patient**

Meeting a patient gives us a quick snapshot of their health at that particular point of time, thus, it is crucial to explore the patient's history to understand the entire picture. Providers are trained to take a thorough

history comprising the patient's medical history, surgical history, family history, and social history. This procedure ensures that all aspects of the patient are considered: biological, psychological, and social. Barbour, an internal medicine physician, studied 400 of the patients referred to his clinic and found that doctors have a preference for using organic illness to explain symptoms leading to misdiagnosis.<sup>6</sup> He challenges doctors to consider psychosocial causes of illness and to tailor management appropriately.

Physicians tend to find evaluating psychosocial issues to be challenging for fear that they may not be able to address these issues adequately. In a national survey of physicians from specialties "for which evidence-based mind-body methods could be considered appropriate adjuncts to care," 25% of respondents indicated that their formal training was helpful versus 44% rating their training as not helpful.<sup>7</sup> Only about half the respondents felt that "they received effective mentoring during residency in diagnosing psychosocial issues."<sup>7</sup> Even more concerning, approximately 1 in 3 physicians believed that integration of these methods would result in small or no improvements in clinical outcomes.<sup>7</sup> Even patients downplay their own psychosocial issues and sometimes misattribute their symptoms to an organic cause.

To meet the psychosocial needs of patients, there is a need to strengthen psychosocial training in medical school, nurse practitioner and physician assistant programs, residency programs, and even fellowship training. There should be more integration of all aspects of patient care in training, including biological, psychological, and social aspects. Practical, consensus-based recommendations have been organized into the mnemonic "CAARE MORE": *C*onnect personally with the trainee; *A*sk psychosocial questions and *A*ssess the trainee's knowledge/attitudes/skills/behaviors; *R*ole model desired attitudes/skills/behaviors; create a safe, supportive, enjoyable learning *E*nvironment; formulate specific *M*anagement strategies regarding psychosocial issues; *O*bserve the trainee's affect and behavior; *R*eflect and provide feedback on doctor–patient and preceptor-trainee interactions; and provide *E*ducational resources and best *E*vidence.<sup>8</sup> This training can be integrated in daily rounds on medicine wards with medical students and house staff. Useful teaching methods include some that raise awareness and change attitudes (asking, promoting reflection, role modeling), some to teach skills (supervised practice, observation and feedback, role play), some to reinforce behaviors (observation, feedback), and others to fill in knowledge gaps (brief didactics, discussion, mini-assignments, readings). Training must also emphasize thorough psychosocial history-taking with direct questions to recognize psychosocial issues, such as those exemplified by this case.

### **Approach to Improving Systemic Safety: Palliative Care and the Interdisciplinary Team Model**

System barriers also contribute to the challenge of addressing psychosocial issues. There may not be enough time during a visit to address the issues, thus physicians tend to focus more on physiological problems. Ambulatory practices may also have limitations on available resources for psychotherapeutic care, social work consultation, or identification of psychosocial problems.<sup>9</sup> Practices may have inadequate continuity or infrequent follow-up with their patients.

To address these system barriers, there must be policies in place to address the restricted time available for visits. Restricted time limits the physician's ability to adequately address all components necessary for optimal care. Interdisciplinary practice incorporates a multifaceted approach to healthcare which is more consistent with a humanistic approach. A multidisciplinary team is defined as a group of healthcare professionals of varied disciplines and roles, working together towards a common goal of providing optimal

care for a patient.<sup>10</sup> This team may include doctors, nurses, social workers, case managers, chaplains, therapists, dieticians, and other healthcare professionals. The need for a multidisciplinary team is especially important in the field of oncology, given the 1.9 million new cancer cases and 608,570 cancer deaths that occurred in 2021.<sup>11</sup> Over the past several decades, there has been increasing attention to improving the quality of life of oncology patients through comprehensive palliative care.

The term “palliative care” is often confused with “end-of-life care” or “terminal care” or “comfort care.” An earlier World Health Organization (WHO) definition limited palliative care to patients who were not responsive to curative therapy.<sup>12</sup> This concept often confused patients, families, and even health care providers who interpreted a palliative care consult as meaning that the patient was in his or her final days of life. As a result of this misconception, most patients are referred too late for palliative care and many patients are never referred at all.<sup>12</sup> In this Spotlight Case, there were multiple missed opportunities to consult palliative care early, including initial hospitalization and as outpatient a year later. More recently, a new consensus has emerged to define palliative care as specialized medical care for people with serious illness that is focused on providing patient with relief from symptoms, pain, and stress of serious illness – no matter the diagnosis and at any stage of illness. It can be provided together with curative treatment by a team of doctors, nurses and other specialists who work with a patient’s doctor to improve quality of life for both the patient and the family. It is recommended to refer patients to palliative care earlier in their course of treatment because difficulties such as chronic pain, emotional needs, and spiritual needs can be better addressed at an early stage.<sup>13</sup> Earlier referrals allow more clear, empathetic discussion between the patient, loved ones, and the palliative care team. Thus, the patients and families will have a better understanding of the natural history of their disease and its prognosis, and the healthcare teams will have a better understanding of the values and goals of the patient.<sup>12</sup>

Palliative care encompasses many different approaches to meet the needs of the “whole” person. A palliative care team provides multidisciplinary, multifaceted care including management of physical symptoms, psychological needs, and social needs. The team works together to share information and develop comprehensive plans. The patient is the final decision-maker, and the team supports the patient by educating them, offering multiple sources for support, and getting to know their goals and values to guide management.<sup>14</sup> In cases such as the current case, when patients have poor mental capacity or are unable to engage in a full conversation about their care, it is important for the team to obtain collateral information from families and/or caregivers in order to avoid an [omission](#) in care. In turn, the palliative care team strengthens communication between the primary team, patients, families, and other professionals who may be involved.

Palliative care is often consulted when a patient is hospitalized; however, the vast majority of chronic illnesses occur at home. There is a major gap in access to palliative care outside the hospital, and it is not uncommon for these patients to be lost to follow-up, as in the current case. Developing a more robust outpatient or home-based palliative team can improve continuity of care by identifying problems before they become severe, thus preventing future ED visits and hospitalizations.<sup>14,15</sup> Some challenges in developing an outpatient palliative care program include inadequate reimbursement, limited space, and insufficient staffing.<sup>15</sup> However, retrospective studies have shown that with outpatient or home-based palliative care, patients with cancer, advanced heart failure, or advanced chronic lung disease experienced improvements in physical symptoms such as dyspnea and sleep, psychological symptoms such as anxiety, spiritual

needs, and advanced care planning, when palliative care was directly involved.<sup>16</sup>

## Take-Home points

- Early assessment for capacity is necessary to determine if a patient has the ability to make fully informed decisions on their management.
- A complete history must include a thorough psychosocial history to identify any potential psychological or social factors that may affect capacity.
- Capacity reflects a spectrum of decision-making ability and providers should enlist the help of a consultant for additional evaluation when appropriate
- Earlier referral to palliative care is recommended to strengthen communication and understanding of management between families and care teams.
- Outpatient or home-based palliative care programs should be utilized to avoid gaps in palliative care after a patient is discharged.

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