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Dead End: Challenges in Healthcare Delivery to Older Adults with History of Dementia and Incarceration

A Case Report

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INTRODUCTION

Access to primary care is challenging for many patients, especially for those with socioeconomic hardships. Many such patients utilize Emergency Departments (ED) for primary care services. It is challenging for ED providers to assess and manage patients with multi-morbidities and complex social needs who are not under the care of primary care physicians. In addition, it is always a challenge to determine a patient's capacity to manage their healthcare and social needs, even more so for patients with mental health or substance abuse disorders. Geriatric EDs can help providers care for such vulnerable patients. The case presented below highlights the impact of some of the social determinants on individual health and the role of a Geriatric ED in caring for such patients.

CASE DESCRIPTION

A 67-year-old man presented in the Emergency Department from a skilled nursing facility (SNF) for acute onset shortness of breath associated with a cough. He had a past medical history of end-stage chronic obstructive pulmonary disease (COPD, GOLD stage 4), coronary artery disease (CAD) s/p stents to the right coronary artery (two months prior to current evaluation), left above knee amputation (AKA) obstructive sleep apnea (OSA), atrial fibrillation, peripheral arterial disease, polysubstance (Tobacco, marijuana, cocaine, phencyclidine) abuse disorder, hypertension, hyperlipidemia, schizoaffective disorder, anxiety, and post-traumatic stress disorder (PTSD). Workup in the ED ruled out a cardiac cause for his symptoms and he was treated for COPD exacerbation with oral steroids. His symptoms improved with treatment, however, he refused to be discharged to the SNF. A geriatric ED consult was requested to evaluate whether the patient was capable of making an informed decision regarding his discharge which uncovered additional medical, functional, and psycho-social issues.

The electronic medical record review revealed that the patient had 18 hospital admissions in the last 6 months. His care was fragmented across three major healthcare systems in the area. He had not been evaluated by his primary care provider after prior hospital discharges. Additional history revealed that he had been incarcerated for felony assault and had served 18 months in jail. He had been released from jail 6 months prior to current evaluation. He had not seen a behavioral health specialist since being released from jail.

The patient endorsed improvement in his symptoms after receiving treatment in the ED. He attributed the symptom exacerbation to not receiving medications in a timely manner at the SNF. He was living in a house with roommates prior to the facility and would go back to them. He endorsed independence in basic activities of daily living. He had a powered wheelchair that aided his mobility. He was able to use public transportation or would ask friends to drive him for groceries and appointments. He received monthly social security income. He had a 16-year-old estranged daughter and was close to his sister but she had her own medical issues and was not involved in his care at times. His niece helped find him accommodation in the house with roommates. One of his roommates would help him take his

medications. He was trying to enroll in the state Medicaid Waiver program so that he was eligible to receive more help at home.

He had a complicated medication regimen with more than 10 medications to be taken daily. He understood the importance of taking his medications but could not recall all names. He had a CPAP machine at home that he used for sleep apnea. He was open to discharge to a different SNF than the one he came from. His other option was to be discharged to his house with roommates and one of his friends would help him with his medications.

A physical exam revealed lungs that were clear to auscultation. He did not require supplemental oxygen. He was oriented to time, place, and person. He denied feeling depressed or anxious. He denied visual or auditory hallucinations. He denied suicidal thoughts. The 4AT score was 3/12 which was negative for delirium. He scored 16/30 on the Montreal Cognitive Assessment. A CT scan of the head done during prior evaluations revealed chronic small vessel ischemic cerebrovascular disease.

The patient was then diagnosed as having mild to moderate stage dementia due to a vascular etiology. Based on the Four Component Model of Decisional Capacity, he was deemed to have the decision-making capacity for his discharge.

The history of incarceration led to extremely limited choices of skilled nursing facilities that were willing to accept his care. He did accept discharge to a facility that was not where he initially presented from.

However, he again presented to the ED on the same day that he was discharged. He was again treated for COPD exacerbation and a repeat capacity evaluation was requested because he refused to be discharged to a SNF. His capacity was intact. With help from Geriatric ED resources, a discharge plan to home with home health and visiting nurse services was finalized.

Despite these efforts, the patient continued to have high utilization of acute health care resources. He had 17 hospital admissions in the six months after the initial encounter described above. The care teams attempted to utilize resources for home care including hospice but that did not reduce the frequency of ED utilization. He was unable to establish longitudinal care with primary care or psychiatry in the outpatient setting. Lack of reliable transportation to and from outpatient appointments was one potential barrier. One probable reason for his seeking care in the ED could be the reliability of ambulance transport to the hospital after calling 911. Telemedicine visits had been scheduled for him, but he could not attend those possibly due to the paucity of reliable internet services or low digital literacy. Poor health literacy and cognitive dysfunction due to dementia contributed to medication nonadherence.

Assessment by the adult protective services showed that his living situation was not safe as there were no modifications for his physical and cognitive deficits. Guardianship was recommended however this process was time-consuming and did not address his current needs. At one point, the patient had agreed to hospice care assuming that it would provide him with round-the-clock home care. He did not agree with hospice philosophy and withdrew from hospice care.

During one of the subsequent ED visits, he was found to be using cocaine. He had to be intubated three times for airway protection during the various ED visits. Eventually, he was evaluated to have lost decision-making capacity due to substance use. A medical power of attorney had been completed during the prior hospitalizations that appointed his niece as the healthcare agent. During his last hospitalization, he was intubated and upon extubating, the family decided on comfort care measures. The patient passed away under hospice care.

DISCUSSION

This case highlights multiple challenges. First, the healthcare system's capability to deliver complex, medical care to patients with cognitive, functional, and social limitations. Despite being in a Geriatric ED and hospital multiple times and having a good understating of medical diagnosis, interventions were not successful in delivering the right level of care because of complex psychosocial needs.

Second, challenges when assessing decision-making capacity for patients with dementia and psychiatric disorders in an acute care environment. Healthcare professionals routinely follow the Four

Component Model of Decisional Capacity. The assessment involves the following four components – Understanding, Appreciation, Reasoning, and Expression of a Choice.[1] In patients with neurological disorders, deficits in reasoning and executive function affect the ability to make decisions. Patients with dementia may lack awareness of one's cognitive limitations (meta- cognition). Meta-cognition allows a patient to adapt their behavior so that events affected by impaired decision-making capacity are less likely to occur.[2] In our patient's case, he was assessed to retain the capacity to make the decision to refuse discharge to a nursing home based on the Four Component Model. However, executive dysfunction from dementia prevented him from fully understanding the steps that would be required for him to stay safely at home. This included supervision of his complicated medication regimen and treatment of his psychiatric conditions as an outpatient.

The third relevant aspect of this case is the lack of resources for post-incarceration care, notably the gap in long-term care services and supports (LTSS) for older adults. These services include skilled nursing facilities, nursing homes, assisted living, adult foster homes and informal care provided by family and friends. Older adults re-entering society face stigma and challenges while trying to access these services.[3] Our patient had been evicted from his apartment while he was incarcerated. Then he moved in with roommates in a house that could not meet his physical (wheelchair accessible) or emotional (companionship) needs. Our patient may have also faced transportation problems while trying to access primary care appointments. Transportation services are offered by insurance providers, but older adults with dementia may find it challenging to set up these services especially without a caregiver.

Lastly, unmet behavioral health needs. Our patient suffered from anxiety, depression, PTSD, polysubstance abuse disorder and reported a diagnosis of schizophrenia. He had not been able to access behavioral health services after being released from jail. The lack of adequate treatment may also have affected his ability to cope with the complexities of life outside the prison and manage his complex medical conditions. A Post Incarceration Syndrome was proposed to describe the psychological trauma inmates with life sentences experience. Our patient may have also suffered from post-traumatic stress related to the prison sentence.[4] Behavioral health problems added another layer of complexity to providing care for this patient.

The case report demonstrates the challenges associated with assessing decision-making capacity in persons with complex health care need and dementia. While the physicians assess whether a patient can decide, we should also consider if the patient has the executive function to follow through on the actions that need to be taken for a particular event to occur. This is especially true in the case of people with dementia where executive function is impaired. This case also demonstrates that although patients may have the capacity to make certain decisions, the ability to carry out the steps required to achieve certain goals are affected by neuropsychological processes which are impaired in dementia. Social factors such as unstable housing, limited or no family engagement and history of incarceration also plays significant role in preventing the allocation of certain resources thus hampering health care systems capability to deliver appropriate level of care needed to support such patients.

The influence of social factors on individual health is demonstrated in this case. There is a concurrent unmet need for behavioral health services for this individual. Patients with a history of incarceration encounter unique challenges while accessing healthcare services and there is a need to implement post- incarceration services that would provide additional housing and behavioral health resources.

For some vulnerable, older adults, the ED serves as the primary site of healthcare access. A Geriatric consult service can provide support to the ED providers in formulating a suitable disposition plan for medically and socially complex patients. The geriatric provider may elicit an initial diagnosis of dementia thus identifying the need for greater social support as highlighted in this case. They can also help with capacity evaluations as the busy ED providers may not have the time or all necessary information to perform such assessments. The geriatric care managers are valuable in identifying community resources that would support the patient and any qualifying insurance benefits. There are many systems level factors that affect health care delivery and geriatric co management can help acute care physicians navigate some of these challenges.

KEYWORDS

Mental health, Substance abuse, Incarceration, Dementia, Decision-making capacity, Geriatric Emergency Department

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