ARTICLE

Ethical Considerations Regarding End-of-Life Planning and Palliative Care Needs in Patients With Chronic Psychiatric Disorders

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It has been well established in the literature that individuals with chronic psychiatric disorders suffer from increased and earlier mortality than the general public (1). Those with schizophrenia die up to 25 years earlier than those without psychiatric disease (2, 3). Numerous factors contribute to poorer health outcomes aside from limited medication compliance, including under detection of medical conditions and detection at more advanced progression. Nevertheless, there is a lack of literature on how to address unique palliative care needs that can present in those with chronic psychiatric disorders and also how to increase utilization of these services sooner in psychiatric patients facing end of life. Palliative care for those with pervasive psychiatric disorders can be ethically challenging for providers, as often the burden toward beneficence is much stronger than the value for autonomy.

ADVANCE CARE PLANNING

To preserve autonomy for end-of-life decisions, patients are encouraged to discuss and document their choices in advance. Psychiatric care for those with chronic psychiatric disorders can often be driven by paternalism, especially when patients decompensate psychiatrically throughout their lives. It can be difficult for providers to re-establish that sense of autonomy for these patients, as often they are thought of as one of the most vulnerable populations. Even when patients have established guardianship, they may still be capable of communicating their wishes. One study included a review of the presence of a documented health care proxy in the medical records of those with chronic psychiatric disorders and found that only 1 in 344 records included such a designation (4). However, a study based out of Massachusetts demonstrated that patients with chronic psychiatric disorders were interested in participating in end-of-life planning with their providers. Out of a sample of 150 patients, 72% believed someone should be designated as a proxy to make medical decisions if they were incapable to do so (5). Complex and often ethically driven fears that patients lack the capacity to understand, such as the permanence of a DNR [do not resuscitate] order, can lead to avoidance. When these discussions do not occur, patients are placed at risk of receiving aggressive and unnecessary life-sustaining measures. Families and providers can be left with the difficult burden of making the decision in acute care settings, which again ultimately favors a paternalistic approach when autonomy is not allowed through advanced planning.

Unfortunately, many patients with chronic psychiatric disorders face complex social issues that can limit treatment decision making. A lack of family due to lower rates of marriage or strained family relationships are factors to consider when aiding someone in choosing a health care proxy (6). In addition, homelessness is a key issue in patients with pervasive psychiatric disorders that must be addressed in the palliative care planning process (2). Forging a relationship with patients and providing support through social work services or emotional care through support groups or chaplaincy services can serve a crucial role in end-of-life planning in those with unstable social situations (7, 8).

SYMPTOM MANAGEMENT

When considering palliative care needs, it is common to address underlying somatic symptoms such as pain, nausea, and energy level, but underlying psychiatric symptoms should also be addressed. When a patient presents with altered mental status, one should be diligent in ruling out potential delirium versus an exacerbation of their prior psychiatric disorder. When underlying psychiatric symptoms such as psychosis, mania, or depression worsen in a palliative setting, aggressive attempts should be made to treat these symptoms to improve quality of life. Patients can be better understood by exploring thought content that overtly appears delusional as a possible disorganized attempt to communicate underlying physical distress. For example, a case report described a patient with schizophrenia and comorbid head and neck cancer who presented with complaints of a fractured face and tongue and was found to have oral thrush and headaches (9). It is well documented that individuals with schizophrenia express pain less often and differently than others, and thus understanding changes in mental status as possible underlying physical distress can help address nonverbal suffering (7, 10).

Refusal of treatment is possible, and when guardianship is not present, capacity should be frequently evaluated. Physicians often are strongly motivated to uphold the oath to heal, and in patients with pervasive psychiatric dis-

orders that drive can challenge patient autonomy when insight and judgment are often impaired. For treatment of psychiatric symptoms with psychotropic medications, legal processes should be reviewed for involuntarily medicating patients. However, mental health providers can educate treatment teams on the use of emergent administration of psychotropic medications. Efforts to alleviate agitation, fear, or anxiety secondary to psychosis can be a palliative-driven treatment to relieve nonphysical pain. As mentioned previously, effectively communicating with patients and building rapport can improve trust, compliance, and ultimately enhance outcomes.

PATIENT-PHYSICIAN RELATIONSHIP

It is important to consider the relationship between the patient and the provider when discussing the palliative needs of those with chronic psychiatric disorders. Underlying psychotic symptoms, such as paranoia or delusional thought content, can impair patients' ability to trust their providers, especially those with whom they are not familiar. In addition, nonpsychiatric providers can often be uncomfortable caring for psychiatric patients and can harbor conscious or unconscious stigma (2). Stigmas include fear of violence, ideas of psychiatric illness directly correlating with mental incapacitation, and overall sense of psychiatric disorders being a burden to care. Psychiatrists can serve as an advocate for patients and attempt to mend relationships with external providers when patients themselves feel prejudiced.

WORKING AS A MULTIDISCIPLINARY TEAM

Collaborative care can bridge the gap between psychiatry and other fields of palliative medicine. A study examining end-of-life planning for psychiatric patients in the Veteran's Affairs (VA) health care system found increased access and advanced planning for end-of-life care among veterans with schizophrenia and terminal illness compared to the general population. These veterans were found to have improved end-of-life planning, with 58% having an advance directive, 63% having a physician DNR order, and 55% ultimately enrolled in hospice (11). The collaborative nature of the VA health system, including partnership with psychiatric providers, appears to have improved outcomes. The study supports the need for collaborative care between psychiatry, primary care, and specialty care providers (e.g., oncology) when addressing end-of-life planning. By incorporating the expertise of various fields, neither the underlying psychiatric disorder nor the terminal condition is neglected.

Respect for autonomy while relieving pain and suffering is an important principle common to both palliative care and psychiatry. Incorporating cross-training between palliative care and psychiatric nursing staff is a means to emphasize common skills in patient care. Integrative training can help prepare nursing staff to address obstacles those with psychiatric disorders can pose in achieving these goals (12). Efforts have also been made to push for an incorporation of palliative care education into psychiatry residency programs. One study found that 97% (N=95) of residents surveyed agreed that they desired formalized palliative care training (13). Mutually, palliative care teams have expressed interest in having psychiatrists more involved, as only 10% of palliative care teams have a full- or part-time psychiatrist employed as a member on their team (14). As the interest in incorporating palliative care into end-of-life planning expands, there is potential for psychiatry to also expand into this growing field of medicine.

TABLE 1. Role of Psychiatrists in Palliative Care

Address end-of-life planning including advance directives.
Evaluate for capacity.
Rule out delirium when psychiatric symptoms exacerbate.
Educate on appropriate palliative use of psychotropic medications.

PALLIATIVE APPROACH IN TREATMENT-RESISTANT PSYCHIATRIC DISORDERS

Although controversial, cases have been reported of severely treatment-resistant psychiatric disorders, such as anorexia nervosa, being converted to a palliative approach (15, 16). Similarly, severe psychosis in patients with thought disorders can lead to refusal of basic needs, such as nutritional intake. Patients' psychiatric disorders can medically place them at risk, at times requiring involuntary treatment. Use of palliative approaches in neurodegenerative conditions, such as advanced dementia, are more widely accepted because there is no effective cure to prevent ongoing mental decline (17). However, in disorders such as anorexia, treatment options are limited, and in cases of the most severe thought disorders, individuals can be resistant to all treatment approaches. Ethically, such cases are challenging. Incorporating ethics committees in cases in which severe psychiatric disorders are solely responsible for the terminal medical decline can help clarify goals and ensure all viable treatment options have been reasonably explored.

KEY POINTS/CLINICAL PEARLS

- Advanced care planning is important to discuss with patients in the outpatient setting to persevere autonomy.
- When exploring palliative care needs in patients with chronic psychiatric disorders, addressing social barriers and lack of support is imperative.
- Incorporation of psychiatric providers into multidisciplinary teams can ensure that both the terminal condition and the psychiatric disorder are appropriately managed.

CONCLUSIONS

There is a lack of research on end-of-life care in those with serious and pervasive psychiatric disorders. Psychiatrists play a key role in the longitudinal care of these patients and can make an impact by incorporating advanced care planning into routine psychiatric care (see Table 1). When facing a terminal illness, addressing underlying mental health needs is crucial in the field of palliation. Further studies are required on how to best deliver palliative care in those with chronic psychiatric disorders. Thus far, collaborative care has proven to be most effective. Psychopharmacology has allowed psychiatry to relieve mental suffering throughout a person's life. However, building relationships through empathic communication and compassionate care can preserve beneficence and autonomy as all individuals, including those with psychiatric disorders, face their end of life.

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