End-of-Life Care for Patients with Schizophrenia #332

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SCHIZOPHRENIA is a chronic and debilitating psychotic illness affecting 1% of the population. Patients with schizophrenia are at risk of receiving worse end-of-life care than other patients.¹ This *Fast Fact* reviews relevant medical evidence and offers care suggestions for seriously ill patients with schizophrenia.

Illness Background

Schizophrenia is characterized by the following.

- *Positive psychiatric symptoms:* These include paranoid delusions and auditory hallucinations that often have a relapsing-remitting pattern and respond to antipsychotic medications.
- *Chronic negative symptoms:* Cognitive changes such as executive dysfunction, amotivation, blunted affect, and social withdrawal are symptoms that are often refractory to pharmacotherapies.
- *Ten–20-year shortened survival:* Medication side effects; a reduced access to medical care; an increased rate of substance abuse (particularly tobacco); and an increased prevalence of comorbid illnesses such as cardiovascular disease, cancer, and emphysema are all contributing factors.^{2–4}

Access to Palliative Care

In the last six months of life, patients with schizophrenia are about half as likely to access palliative care specialists.¹ In addition, they receive less opioid analgesia, have a higher likelihood of spending extended time in a nursing home, and are less likely to engage in advance care planning despite evidence that many schizophrenic patients are capable of doing so.^{1,5}

Determining Capacity

Many patients with schizophrenia retain capacity for medical decision making, especially when the support of trusted providers, friends, or family is sought out.^{6–8} Some patients who lack capacity to make complex medical decisions, such as determining code status, may nonetheless retain capacity to make less complex decisions such as designating a surrogate decision maker.⁹ Because symptoms of schizophrenia can make the determination of capacity challenging, psychiatric consultation is often essential.¹⁰ Some patients with schizophrenia will have legal guardians who may be a family member or a nonfamily member appointed by the legal system. Depending on state laws, guardians may be limited in their capacity to withdraw life-extending treatment such as artificial feedings.^{9,11} In such cases, involvement of social work and bioethics may be necessary.

Advance Care Planning

Even when patients with schizophrenia are medical candidates for life-extending treatments such as dialysis or chemotherapy, psychotic symptoms such as paranoia may make them unwilling to cooperate with treatment, requiring ethically problematic interventions such as the use of restraints or sedation to deliver treatment. This can generate conflict about the best treatment course and necessitate the involvement of psychiatry and clinical ethics consultants.

- Outpatient discussions regarding potential conflicts with the patient and/or surrogate should occur before an acute medical or psychiatric crisis.⁹
- Psychiatric-specific advance directives exist that detail not only medical contingencies but also psychiatric treatment preferences and outpatient mental health providers (e.g., case managers and group home staff) in the event of a psychiatric decompensation.¹² Although supporting data on these tools are inchoate, they may reduce violent episodes and need for crisis management.^{13,14}

Pain Management

Schizophrenic patients often struggle to recognize and report pain,^{15,16} especially in inpatient settings when cared for by clinicians unfamiliar to them. The Pain Assessment in Advanced Dementia Scale has been utilized even though it was neither designed nor validated for this patient population.¹⁶ Otherwise, engaging longstanding caregivers in symptom assessment may foster trust and empower patients to share their symptoms more openly.

Psychiatric Care

Antipsychotic dosing may be much greater for schizophrenia (haloperidol doses of 20–30 mg/day are not uncommon) than for treatment of delirium, agitation, or nausea. Antipsychotics exhibit dose-dependent QT prolongation and resultant risk of torsade de pointes, which can be worsened when combined with other QT-prolonging medications such as antiemetics, methadone, and antibiotics. In patients with estimated survival longer than a few months, recurrent ECG monitoring may be necessary. Clinicians should be cautious about deprescribing antipsychotics, however, in patients who are not imminently dying, as the stress of medical illness may worsen positive psychiatric symptoms. If a medical issue arises in a schizophrenic patient who is not imminently dying, preventing intake of the oral psychopharmacological regimen, psychiatric consultation should be considered.

Psychosocial Support

Schizophrenic patients are at risk for poverty, homelessness, hunger, and violence.^{17–19} Such concerns can be primary drivers in medical decision making. Unfortunately, finding safe and appropriate care settings can be challenging for terminally ill patients with schizophrenia. Psychiatric group homes and inpatient psychiatric care settings may be poorly equipped to offer a sufficient end-of-life care plan and environment; conversely, hospices or nursing homes may be poorly equipped to address uncontrolled psychiatric symptoms. Thus, patients with schizophrenia may be at heightened risk for prolonged hospitalizations at the end of life. Social workers, chaplains, psychiatrists, and/or community case managers may be able to clarify unmet psychosocial and spiritual needs.¹⁹

Summary of Key Points

- Schizophrenic patients are at risk for suboptimal symptom control and unmet psychosocial needs.
- Schizophrenic patients do not inherently lack capacity, but may require medical explanations and advance care planning for medical and psychiatric contingencies “early and often.”
- Involvement of multiple disciplines including psychiatry, social work, trusted outpatient providers, and clinical ethicists may be necessary.

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