Palliative Care for Terminally Ill Individuals with Schizophrenia

ABSTRACT

Individuals with schizophrenia are often medically undertreated and experience symptoms that interfere with communication and the capacity to make medical decisions. These issues complicate quality end-of-life care for this population and are of particular concern for hospice and palliative care nurses and health care providers. This article presents a case study of a terminally ill patient with schizophrenia. It is divided into a series of vignettes; each vignette presents a common clinical issue encountered by the palliative care team. Interventions suggested in the literature and those used by team members when working with the patient are discussed. [Journal of Psychosocial Nursing and Mental Health Services, 52(8), 32-38.]
The U.S. health care system has placed greater importance on the delivery of quality care to individuals who are terminally ill. Palliative care emphasizes the relief of symptoms but does not require that an individual have a terminal illness. This type of care is appropriate for any patient at any stage of a serious medical illness and can be provided at the same time as curative, life-prolonging treatment (Terpstra & Terpstra, 2012). Palliative care seeks to relieve suffering through early identification, assessment, and treatment of pain and other symptoms of a physical, psychosocial, or spiritual nature (World Health Organization, 2012). Hospice care is also focused on providing comfort, but primarily for patients with terminal illness who are no longer seeking curative care and whose prognosis is death within 6 months.

The authors of the current article are all hospice and palliative care clinicians who have encountered several terminally ill individuals with schizophrenia. Approximately 6% of adults (1 in 17) are diagnosed with serious and persistent mental illness, and 90% of those with serious and persistent mental illness have schizophrenia (McCasland, 2007). Individuals with schizophrenia have long been undertreated or have avoided treatment, particularly at the end of life (Baez & Avery, 2010). Symptoms of schizophrenia can have an effect on physical health and the ability to respond to disease-modifying treatments. These symptoms can also interfere with the capacity to make medical decisions, communicate effectively with caregivers, and reach treatment goals (“Integrating Mental Health Services,” 2009).

The current article explores a case study of a patient with metastatic terminal lung cancer who also has schizophrenia. It is divided into a series of vignettes; each vignette presents a common clinical issue encountered by the palliative care team. Interventions suggested in the literature and those used by team members to treat this patient are discussed.

**CASE STUDY**

**Late Presentation**

The case study patient was a 61-year-old man with a history of paranoid schizophrenia, anorexia, heavy smoking, and polysubstance abuse (in remission). He demonstrated paranoid delusions and auditory hallucinations at baseline. He was a long-time resident of an adult foster care (AFC) home, and he had a legal guardian.

The patient was routinely seen at a large medical center’s mental health and primary care clinics. He was seen twice monthly at the mental health clinic for depot injections of an antipsychotic medication. Most recently, he visited his primary care provider (PCP) with a caregiver—he reported a new onset cough but denied any other symptoms. The examination was documented as benign.

One week after the visit with his PCP, the patient was escorted to urgent care at the same medical center with complaints of hypotension and new onset left-sided weakness. He was transferred to another hospital, where a detailed work-up revealed bladder carcinoma, chest lymphadenopathy, and multiple brain masses. He underwent brain irradiation. His course was complicated by the development of pulmonary emboli and deep vein thrombosis, for which he received lengthy inpatient treatment.

The vignette above indicates that the patient was diagnosed with advanced metastatic cancer very late in the disease trajectory even though he was routinely, and even recently, examined by his PCP. Many reasons exist for this. In this case, it appeared that the mental illness itself may have led to atypical and late presentation of symptoms.

Individuals with schizophrenia sometimes do not willingly verbalize their pain or related symptomology even with advanced illness and are more tolerant than the general population of non-healing lesions and tumors on their bodies (Goldenberg, Holland, & Schachter, 2000). This muted response may be an expression of the negative symptoms of schizophrenia, or it may be that these individuals integrate the pain and other symptoms into their delusional system, which distorts their understanding and recognition of them and effects how these symptoms are communicated to a provider. Jeste, Gladjo, Lindamer, and Lacro (1996) demonstrated that the more severe positive symptoms an individual with schizophrenia has, the more likely it is that symptoms related to a concurrent medical illness will be underestimated or ignored. This lack of awareness delays evaluation and management and often results in palliative care becoming the first line of treatment for some of these individuals (Goldenberg et al., 2000).

The relationship between mental illness and poor physical health is well documented in the literature. Carney, Jones, and Woolson (2006) conducted a population-based controlled study using a 100% sample of Blue Cross/Blue Shield of Iowa administrative claims from 1996 to 2001. The study specifically examined those individuals diagnosed with schizophrenia; more than 1,000 men and women were identified with this mental illness. Those with schizophrenia had three or more medical conditions/diseases compared with those without schizophrenia. These medical conditions included liver disease, stroke, emphysema, renal failure, and diabetes.

Compared with the general population, individuals with serious mental illness have a reduced life expectancy of 25 years (Parks, Svendsen, Singer, & Forl, 2006). Despite the known increased morbidity and mortality associated with mental illness, individuals with schizophrenia are less likely to...
be screened for cancer or have routine check-ups. Psychiatrists may be reluctant to perform physical examinations on individuals with mental illness who appear unwell, and medical providers sometimes attribute physical symptoms to the mental illness and do not address them appropriately.

The lifestyles of those who are chronically mentally ill are often unhealthy, characterized by less exercise, more smoking, alcohol abuse, and poor diet. A high rate of substance abuse also exists among this population, which may be a result of attempts to self-medicate symptoms or the side effects of antipsychotic medications (Ellison, 2008). Madrigal (2008) reported other lifestyle factors, such as poor attention to hygiene and grooming, discomfort with seeing a physician, a lack of available medical services, poor insurance coverage, and a lack of transportation.

In addition, antipsychotic medications used to treat mental illness can adversely affect physical health. These medications can cause weight gain, hyperlipidemia, hypertension, cardiac arrhythmias, prolonged QT intervals, aspiration, and even sudden cardiac death (Madrigal, 2008; Robinson, 2008). In one research study, 370 individuals with schizophrenia were followed for 13 years, and causes of avoidable natural deaths among the population were examined. These causes included failed recognition of medical disease by the individual or caregiver, missed medical diagnosis, develop somatic diseases, it is sometimes difficult for them to be admitted to an open or general medical unit because it can be problematic to treat and manage them in this setting. Safety is of primary concern for the individual and staff. The patient had a variety of complicated medical and psychiatric problems, but his symptoms were such that he could be managed in the open hospice and palliative care unit by the palliative care team, which included a psychiatrist, acting as consultant liaison, and a psychologist.

It is not always feasible to care for a physically ill patient in a psychiatric unit (Inagaki et al., 2006; Kelly & Shanley, 2000). With the introduction of psychologists to palliative care teams and the use of psychiatric consultant liaisons, the success rate of these teams to care for terminally ill individuals with schizophrenia outside of psychiatric units is improving. Baker (2005) proposed that palliative care teams incorporate advance practice nurses who specialize in psychiatry to provide expertise in mental health care.

Conversely, situations exist when specialized psychiatric care may take priority. For example, if a majority of the individual's symptoms are believed to be related to an exacerbation of the psychiatric illness, psychiatric hospitalization may help stabilize these symptoms first. In addition, some patients may be more familiar with the psychiatric staff, and the environment may help minimize the trauma of the hospital admission and any ensuing treatment. Familiarity with staff and the environment may help them more freely express anxieties and concerns to trusted staff. A study by McGrath and Holewa (2004) found that staff in one forensic mental health facility who kept and cared for their own patients who were terminally ill had an inherent understanding of the person-centered approach. Staff members were more distressed when patients they knew well were moved to another facility for hospice care—the staff had become the “family” for many of these patients.

Finally, if the inpatient mental health unit is attached to the hospital, an active palliative care liaison team can help co-manage the physical symptoms until hospice admission is appropriate (Kelly & Shanley, 2000). Terpstra and Terpstra (2012) discussed several strategies for integrating hospice and palliative care and mental health treatment, including recognizing the similarities between the two approaches so that collaboration is facilitated, cross-training palliative care and mental health clinicians, and generating more research and publications on the topic.

**Medication Management**

On admission, the patient was noted to be alert and oriented to name and place, but not to time. He was cachectic; his oral intake was poor; and his thought processes were disorganized. He informed the examiner that he had received cobalt treatments to his...
Medication management for terminally ill patients with schizophrenia can be difficult for many reasons. The stress of inpatient care can sometimes precipitate a psychotic episode, delirium, or both. It is important to explore with family and caregivers the individual's baseline behavior and how the current presentation differs. Palliative care providers should conduct serial physical examinations to get to know the patient well over time. Doing so will enhance the ability of providers to recognize even subtle changes, which may represent drug interactions, side effects, or raise suspicion for delirium related to an underlying medical cause (e.g., urinary tract infection, pneumonia).

Sometimes, the psychotropic medication regimen is altered or discontinued during a hospitalization for a medical illness. Medication reconciliation should involve a review of medications prescribed in the acute setting, as well as those prescribed prior to hospitalization. Restarting previously effective psychotropic agents at comparable doses may be necessary, allowing time to establish efficacy (Dementia Education & Training Program, n.d.).

Terminally ill patients often have new medications added for symptom management. Neuroleptic levels may fluctuate from alteration in drug metabolism induced by these new non-psychiatric medications. In addition, potential drug interactions can occur between psychotropic and non-psychotropic agents. Cachectic terminally ill individuals may have more free drug available in the blood stream, and doses need to be adjusted downward accordingly.

Medication noncompliance is also a common reason for symptom manifestation and behavioral decompensation. Patients with paranoia may refuse to take their medications or hide them in their cheeks. Switching to depot, rapid disintegrating, or liquid forms of medications may be necessary to enhance compliance. Conversely, if compliance with oral medications occurs, switching from a depot to oral form allows for more careful titration over time.

Medically used psychotropic medications (i.e., those used as antiemetic drugs) with antidopaminergic properties can also cause extrapyramidal side effects. The anticholinergic burden from multiple medications should be calculated, and pharmacotherapy should be adjusted, if possible, to lighten the burden.

The psychiatric consultant liaison simplified the medication regimen for the patient. The depot antipsychotic medication was converted to daily oral medication for ease of titration. A medication was weaned and discontinued. The patient was prescribed an antidepressant medication, which could also help with his anorexia. Behaviorally, the patient was managed successfully in the open palliative care unit until his death.

What About Smoking?

The patient had a history of heavy cigarette smoking. He desired to smoke almost constantly and told staff that he felt smoking made him feel alive. A smoking risk assessment was completed on admission, and he was deemed to be a safety risk for independent smoking. The patient was asked about smoking cessation options, but he stated he was not interested.

The incidence of smoking among individuals with schizophrenia is high; it is believed to be between 70% and 90% (Griffith, 2007). This figure is approximately three times higher than the general population. Individuals with schizophrenia who smoke are also heavier smokers than those in the general population, as well as those with other psychiatric disorders (Kelly & McCreadie, 2000).

Several possible explanations for the high prevalence of tobacco use among individuals with schizophrenia are reported in the literature. First, aspects of the illness itself may cause increased smoking. Some individuals may smoke as a form of self-medicating with nicotine. Smoking results in the release of more dopamine from the prefrontal cortex, which helps alleviate both positive and negative symptoms (Kelly & McCreadie, 2000).

In addition, it has been suggested that nicotine may have antidepressant effects (Brown & Action on Smoking and Health Scotland [ASHScotland], 2004; Kelly & McCreadie, 2000). Individuals with schizophrenia who smoke have reported relaxation and calming their nerves as reasons for tobacco use (Kelly & McCreadie, 2000). Smoking may also be used as a coping mechanism to help deal with the stresses of living with mental illness or financial hardship. However, a cycle may ensue whereby nicotine stimulates a more immediate relaxed, alert state, which eventually leads to withdrawal symptoms, increased cravings, and agitation. Therefore, more nicotine is needed to calm the anxiety (Brown & ASHScotland, 2004).

Individuals with schizophrenia may also smoke heavily due to prescribed antipsychotic medications. Most of these medications cause dopamine-receptor blockade, and it is theorized that a high level of smoking is needed to overcome this blockade and achieve the reward effects of nicotine (Kelly & McCreadie, 2000). Interestingly, individuals with schizophrenia who smoke have been found to have an earlier onset of illness, increased number of hospital admissions, and receive higher doses of neuroleptic medications (Dalack & Meador-Woodruff, 1996). Therefore, smoking may be a marker of a more severe illness process.

Controversially, it has been hypothesized that smoking may increase vulnerability to some mental health disor-
KEYPOINTS

1. Individuals with schizophrenia are often medically undertreated.
2. Compared with the general population, individuals with serious mental illness have a reduced life expectancy by 25 years.
3. Placement, pain and symptom management, and communication can be challenging when caring for individuals with schizophrenia at the end of life.
4. Death does not differentiate between those who have mental illness and those who do not.

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Schizophrenia and Pain
The patient had widespread carcinoma with brain metastasis. He told the provider on admission that his tongue and face were fractured. He also adamantly denied pain at that time. Later in his stay, his reports of pain were always vague, as he rubbed his hands over his chest and abdomen, stating that it is “always here and always there.” As his condition deteriorated, the patient reported a heart attack, but when questioned about worsening pain, he told his provider to stop asking about pain, as he was not experiencing any pain.

Bonnot, Anderson, Cohen, Willer, and Tordjman (2009) reviewed the literature related to pain and schizophrenia. They found many case reports of individuals with schizophrenia with painful medical conditions (e.g., appendicitis, perforated bowel) with no reports of associated pain. They also found little or no physiological evidence to support pain insensitivity among this population. Instead, a decrease in the behavioral response to pain exists, which is most likely related to the different ways these individuals express emotions in general and pain specifically. The exhibited disturbances in communication can lead to delayed recognition and treatment of serious illnesses and, unfortunately, increased morbidity and mortality.

In most smokers, the 1A2 pathway is energized, and higher doses of some antipsychotic medications metabolized via the P450 system are required for smokers than nonsmokers. Smoking has also been tied to hyponatremia in smokers (Freudenreich & Stern, 2003). The authors of the current article agree with the different ways these individuals express emotions in general and pain specifically. The exhibited disturbances in communication can lead to delayed recognition and treatment of serious illnesses and, unfortunately, increased morbidity and mortality.
Stanghellini (2009) discussed the disembodiment of individuals with schizophrenia and described the experience as a world in which the individual lives and behaves like a soulless body. A detachment from the self, actions, and experiences occurs, and conceptually, the seam that connects the body and the mind is torn. Individuals with schizophrenia then live as mere spectators of their own perceptions, actions, and thoughts. If this experience is the case, it is understandable that the behavioral response to pain would be muted or different.

In the patient’s case, assessment of pain symptoms was challenging. His reports of the tongue and face fracture prompted concern for continued headaches, oral thrush, and aphthous ulcers, as he was still taking steroid agents. His unique way of communicating his symptoms gave some focus to the physical examination and subsequent treatment. Likewise, the claim of a heart attack and then his denial of pain led to concern for increased chest pain related to his lung masses and resulted in the adjustment of his pain medication dosing.

Other theories exist regarding the muted response to pain. Autié et al. (2009) identified two different facets of the expressions of pain among this population. First, a biological dysregulation in n-methyl-D-aspartate may exist. Second, an apparent psychological indifference to external stimuli exists. Differences in the biological, cognitive, and emotional functions among individuals with schizophrenia affect both the sensory discrimination of the stimulus and the interpretation of it. Others postulate that pain results in noxious physical or psychological stress, which cannot be released through normal behavioral responses by regular mechanisms and instead may be a key factor in the onset or relapse of schizophrenia (Bonnot et al., 2009). With this latter theory in mind, clinicians should monitor behavioral disturbances or increases in symptoms of the mental illness, as these may be signals that pain is not being managed sufficiently. Webber (2012) reported that among individuals with schizophrenia, delusions may not change in theme but may become more intense as a coping response to a stressful event. An escalation of the delusional behavior in an individual with schizophrenia and terminal illness may indicate increased distress.

Listening carefully and interpreting communication was key with the patient. When he complained that his face and tongue were fractured, the physical examination focused on any sources of pain from the head and neck. The examination revealed oral thrush, which could be treated. Further gentle questioning of the patient elicited complaints of a headache. Long-acting opioid agents and short-acting breakthrough opioid agents were prescribed for pain, along with other adjuvant medications. The breakthrough medications were ordered in such a manner that staff were to offer the medication at regular intervals and elicit the need for the medication or a refusal. The patient did not seem to understand or appropriately use the numeric pain scale; instead, the faces scale was used when he was more alert, and later, when his condition deteriorated and he was not communicative, the Pain Assessment in Advanced Dementia Scale (PAIN AD; Horgas & Miller, 2008) was used. This scale is a behavioral observation tool designed for use with individuals with advanced dementia who have trouble communicating pain. The patient, of course, did not have dementia; however, the team found the tool useful with his unique circumstance.

**DISCUSSION**

The current article does not cover all of the issues that hospice and palliative care teams encounter when caring for this challenging population. McCasland (2007) discussed approaches when working with patients experiencing delusions and hallucinations. Cross and Rudnick (2010) studied coping mechanisms among patients diagnosed with schizophrenia first and then cancer.

A plethora of literature exists on the topic of capacity with regard to medical decision making in mental illness. In the current case, the patient had a well-established legal guardian who knew him well and was active in his care. However, this is often not the case. Autonomy or self-determination is an issue that surfaces frequently in psychiatric illness for a number of reasons. Sometimes, individuals do not realize they have a terminal illness, which prevents them from understanding and deciding among treatment options. Others lack decision-making capacity if their mental illness affects reasoning. Variable capacity over time makes it challenging for providers to sort out end-of-life decisions for this population (Webber, 2012).

Researchers have found that individuals with mental illness who have the greatest degree of physical impairment are the most receptive to talking about end-of-life decisions and advance directives (Foti, Bartels, Merriman, Fletcher, & Van Citters, 2005). Tailoring end-of-life information to enhance a discussion between the provider and patient and facilitate the patient’s simple understanding, if possible, is recommended (Wood, Willison, Kington, & Gavin, 2008).

**IMPLICATIONS FOR NURSING PRACTICE**

Nurses are often involved in the care of individuals with schizophrenia in various settings. It is important that nurses are aware of the increased morbidity and mortality rates among this patient population, as well as the reasons for these increased rates. Awareness is one important step toward improvement in provision of care. Nurses providing end-of-life care to patients with schizophrenia can use knowledge of the muted response to pain and other symptoms to adjust assessment techniques to better detect the sometimes subtle signals that problems exist.

The clinicians who authored the current article have noted in practice that one important parameter that can serve as a harbinger to potentially serious medical issues among older adults with schizophrenia is patient’s weight, or more specifically, an unexplained downhill trend in the weight record. This de-
cline should prompt a discussion about oral intake, dysphagia, pain, and any other new symptomology. The authors suggest that the correlation between unexplained weight loss among older adults with schizophrenia and a subsequent finding of serious medical illness serve as a topic for future research.

Sharing successful, as well as unsuccessful, interventions when working with this patient population in hospice and palliative care can help other clinical teams experiencing similar challenges.

CONCLUSION

The clinical team working with the patient concluded that his care was challenging yet rewarding. A pressing need exists for more information about the unique end-of-life care needs of individuals with schizophrenia and concomitant terminal illness. As noted previously by the authors of the current article, death with dignity is something one desires for oneself and for loved ones, and death does not differentiate between those who have mental illness and those who do not (Terpstra & Terpstra, 2012).

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