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ESSAY/PERSONAL REFLECTION

Proactive: Spiritual care for terminal restlessness

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According to the *Journal of Pain and Palliative Care Pharmacology*, 25–88% of all hospice patients, caregivers, and hospice staff will observe significant changes in a patient's behaviors. Some of the changes include picking at sheets or Depends, restlessness movements of the arms and legs, confusion, tight clutching at caregiver's hands, and twitching and jerking. These signs are usually categorized as terminal restlessness. Sometimes, the cause is a medical condition that can be treated.

Pain is one of the most common medical causes of terminal restlessness. The team of nurses, social workers, and chaplains all watch for signs of pain during visits, and teach families how to assess a patient's pain level. Pain is one of the causes of terminal restlessness. Various other conditions, for example, hypercalcemia, encephalopathy, shortness of breath, or side effects from medications, may also cause some of the symptoms of terminal restlessness.

There are cases where the cause is not medical, it is spiritual. Spiritual causes for terminal restlessness are possible to assess and address early in hospice care. Assessing and addressing the underlying spiritual causes of terminal restlessness create a more positive hospice experience for the patient, caregivers, and hospice staff. A hospice may be able to save on medication expenses, on-call visits, and crisis staff time with a skillful spiritual assessment and the chaplain's work with the patient and caregivers on these underlying causes. First, the patient and caregivers need to be encouraged to accept a chaplain visit as part of their hospice experience. The admitting nurse can explain about each team member having a part to play in hospice being as positive an experience as possible. This sets the stage for patient and family acceptance of a chaplain visit during the admission process.

To effectively incorporate the chaplain's role, the admitting nurse lets the patient and caregivers know, during the admission visit, that the chaplain will be calling to schedule a spiritual assessment. The hospice spiritual assessment needs to be more than the patient's religious affiliation, desire for prayer, and learning if they would like their priest, pastor, rabbi, or bishop contacted. Patients and caregivers usually readily accept the chaplain once they meet face to face for the spiritual assessment.

During this initial visit, the chaplain encourages the patient to tell the story of their illness, what being ill has meant to their lives, and how others have responded to their illness. Listening, noting changes in feelings and body language and gaps in the story, guides the chaplain regarding the meaning illness and dying have for the patient, and what, if anything, redeems their suffering and losses. The chaplain listens and may ask how the patient feels about how each family member has responded to their diagnosis and prognosis and what concerns they have for each person. Reluctance to cause family members pain by dying is a cause for spiritual terminal restlessness. Another is concern about how a family member will be taken care of after they die.

The chaplain's job is naming and accepting the choices a patient has made without judgment. If the patient wishes, the chaplain assists them in exploring fears, forgiveness, redemption, and what healing the past means to the patient. This is possible, even in a very short-term hospice relationship. The process is not a psychoanalytic exploration. It is an intense and usually brief focus right at the heart of their regrets, memories, questions about a higher power, fears, sense of power and powerlessness, and what they have experienced love to be. Something about the process of being referred to hospice and

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really considering the prospect of dying makes this intense intimacy possible quickly compared to the usual circumstances of people getting to know each other. The chaplain's role is not about advising, intervening, or even offering insight. The chaplain is to listen to whatever the patient chooses to share, and ask what the patient intuits they need to die peacefully.

Other spiritually related causes of terminal restlessness are unresolved issues related to posttraumatic stress syndrome. Questioning the patient, and the family, about combat experience, abuse as a child or as an adult, being a crime victim, having committed crimes, a history of drug/alcohol addiction, and surviving a natural disaster are other causes of terminal restlessness. A clue to how these unresolved issues in a patient's history can cause the symptoms of restlessness can be found in Eastern medicine.

An Asian perspective of terminal restlessness relates to energy movement throughout the body. This "energy" is not directly identified with the nervous system, but rather with something called *pitti*. *Pitti* translates as *wind*. Winds are said to move through the body when emotions are aroused. Blockages in the movement of the winds results in too much energy building up in one area and a deprivation of energy in another. If patients have "unfinished business," their emotions stir the winds, the winds cannot flow freely and smoothly, and the patient develops the signs of terminal restlessness.

Another stirring of restlessness from *pitti* comes from sensory stimuli. Patients readily respond to questions about their feeling hypersensitive to sights, sounds, smells especially, tastes, and touch. When asked, many patients report noticing noises more, for instance, and feeling an almost physical impact from sound. Many wondered about the cause. Their sensitivity to light, movement around them, smells, and people touching them or their bed is almost inevitable at some point in the hospice stay.

Families are usually eager to develop an awareness of the patient's reactiveness. Knowing how to mute the environment, redirect agitated or demonstrably grieving people, and help the patient calm down gives them a tangible way to help the one they love. They like learning to assess the environment from the patient's experience of it, and with that knowledge they can quell disturbances. Families can also avoid burnout from feeling upset and fatigued from caring for a loved one with terminal restlessness. If they know how to match their breath to the patient, so both of them can calm down, and sit quietly at the bedside, they avoid getting up and down or feeling frustrated and discouraged with the patient's restlessness.

If full-blown terminal restlessness arises, caregivers can also learn to sit, quieting their thoughts, and breathe with the patient. Usually within 10 min the patient settles into a more restful state. If the patient and family are taught the possibility of these symptoms, and how to manage them, and practice before there is a caregiving crisis, the hospice saves on emergency visits.

The prescription of sedating medications in high dosages is a common response to terminal restlessness symptoms, and may sometimes be a last resort. Unfortunately, sedating medications in the higher dosage ranges can put the patient's body into a "push me–pull you" by blocking *pitti*. *Pitti* wants to move freely, and the medications want to mute. Pain needs to be treated, but upping dosages only for terminal restlessness may backfire. The hospice may be able to reduce their medication expenses if the team approaches restlessness proactively through spiritual assessment, an active role for the chaplain, and training of the caregivers.

Setting up during admission for the chaplain to visit at least once is the first step is this proactive approach. The chaplain has to use a good hospice-oriented spiritual assessment tool and complete the interview. And, finally, offering the patient and caregivers information on the spiritual causes of terminal restlessness and ways to practice coping before a crisis makes a more positive experience for the hospice team and the family.

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