The Importance of Understanding Advanced Dementia and Hospice

Moments of Life | NHPCO

Caring for a person with Alzheimer's disease or another type of dementia poses unique problems, one of those being the presence and management of neuropsychiatric behaviors. These symptoms include personality changes; loss of communication; loss of inhibition; agitation, anxiety and other mood disturbances. Ultimately in the later stages of the disease, neuropsychiatric behaviors are partnered with physical decline.

Problems with Behavior and Predictability

It is the behavioral problems, however, that are the most common and burdensome to caregivers. Behavioral disturbances, specifically aggressive behavior, have been identified in approximately 40 percent of people with dementia. It is also important to note that the stages of dementia are not entirely predictable in all patients, but it is well documented that patients with end-stage dementia that have received supported services such as hospice may have fewer unmet needs.

There is a great range of behaviors that affect the patient's quality of life (e.g., wandering, sleep problems, depression, delusions, irritability, anxiety, disinhibition), so healthcare professionals must utilize different measures to assess them. Ideally, the goal for any patient with dementia is the promotion of quality of life and well-being.

Promoting Quality of Life and Well-Being

Quality of life for people living with dementia is strongly influenced by communication and social relationships. Thus, it is fundamental to any caregiving experience that practitioners use techniques and skills that enhance communication and contribute to the patient's daily joy.

It is common for patients with dementia to exhibit poor well-being, either from physical pain and/or psychological distress. The deterioration of communication in most patients requires health professionals to use well developed skills of assessment to ascertain the source of distress. The goals of care should be developed in partnership with a full care team that includes the family, the caregivers, and any previously reported preferences from the patients themselves.

Pharmacological and Non-Pharmacological Interventions

There should also be a partnership between pharmacological and non-pharmacological interventions to help address the multiple risk factors and symptoms associated with advanced dementia. The utilization of non-pharmacological interventions—such as aromatherapy, music therapy, touch therapy, enhanced non-verbal communication techniques and spiritual activities—have potential for addressing unmet psychosocial needs. The assessment of neuropsychiatric symptoms, coupled with quality care planning that includes non-pharmacological techniques, can make goals possible that address quality of life. Evidence is also mounting that the distress seen in advanced dementia when left untreated contributes to the poor health outcomes of the patients' caregivers.

Hospice Supports Patients with Dementia

The use of hospice services among the dementia population has grown steadily in the last five years, including use among Medicare decedents with advanced cognitive impairments. For example, in 2001, only 14.4 percent of Medicare decedents with a dementia diagnosis received three or more days of hospice care. By the year 2007, that proportion had grown to 33.6 percent.

Addressing Distress through Hospice and Palliative Care

Palliative care and hospice care can play a significant role in addressing physical, emotional, and spiritual distress during advanced dementia. Supportive programs that are based in a firm understanding of the clinical progression of the disease are more likely to provide the physical and emotional comfort needed at the end of life.

With the growing number of people living with dementia, there is a strong and compelling directive for all healthcare providers to help promote quality of life and reduce distress throughout the clinical course of these dementias.