National Hospice and Palliative Care Organization
Palliative Care Resource Series

PALLIATIVE INDICATORS IN LONG TERM CARE

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CURRENT SITUATION

Approximately 1.7 million individuals in the United States reside in long term care facilities (Ersek and Carpenter, 2013). Annually, 25% of all deaths occur in these facilities. By 2030, it is estimated that at least 40% of Americans will die in nursing homes. (Swagerty, 2014). Today more than half of long-term care patients are totally dependent or need help with their activities of daily living (ADLs). If predictions hold true, 70% of individuals with advanced dementia will die in nursing homes (Ersek and Carpenter, 2013).

Almost twenty-years ago, a "Bioethics Forum" article maintained that "The usual dying experience in a nursing home is cold, lonely, and painful" (Reynolds, 1999). It is unlikely that these same facilities are prepared to house a burgeoning elderly population that will be living with chronic and terminal illnesses. A recent study indicated that 80% of patients residing in nursing homes could benefit from palliative care (Carlson, Lim, and Meier, 2011).

This paper will introduce the unmet palliative care needs of patients in long term care; describe how palliative care can help; discuss ways to identify appropriate patients and offer potential strategies to address the palliative care needs of these patients.

UNMET NEEDS

Daily episodes of pain are not being effectively treated amongst patients in long term care. Data show that pain is a prevalent issue for 49% to 83% of long term care residents.

▪ Half of long term care residents experiencing pain receive analgesic prescriptions PRN (as needed).
▪ Another 25% report experiencing daily pain and have no analgesic medications prescribed (Parker, 2012).
▪ 4% of residents experience excruciating pain on a daily basis (Carlson, Lim, and Meier, 2011).
▪ Eighty percent of patients with end-stage heart failure will have pain.
▪ Sixty-three percent will die with shortness of breath and up to 70% will suffer from some form of depression (Smucker, 2010).
▪ Most of these patients receive scant attention to advance care planning and decision making at end-of-life (Carlson, Lim, and Meier, 2011). This often leads to unnecessary and undesired treatment for these patients.

With multiple co-morbidities, cognitive impairments, challenges in assessing pain, and facilities with high turnover rates, we are on the verge of a crisis in effectively treating vulnerable patients who are often unable to verbalize their needs, wishes and medical problems.

PALLIATIVE CARE CAN HELP

A recent study in the *Journal of the American Geriatrics Society* (Miller, Lima, Interactor, Martin, Bull, and Hanson, 2016) of 1500 nursing home patients in two states indicated that palliative consults in long term care facilities have impactful outcomes.

▌ Of patients who received palliative consults 8-30 days before death, only 11.1% were hospitalized in the last week of life as compared with 22% who did not receive palliative care consults.
▌ The further upstream the consults occurred the better the outcomes. Those who received consults 61 to 180 days before death had a reduced rate of hospitalization in the last week of life of 6.9% compared to a 22.9% rate of hospitalization for patients who did not receive a palliative consult while in the nursing home.
▌ In the last 30 days of life 37.63% of non-hospice patients and 23.18% of hospice patients were hospitalized.
▌ The study went on to reveal that every 10% increase in hospice population in a nursing home led to a reduction in hospitalization risk of 5.1% for non-hospice patients and 4.8% for hospice enrolled patients (Zheng, Mukamel, Friedman, Caprio, and Temkin-Greener, 2015).
▌ Thus, there is an overall blanket effect on the entire nursing home population (hospice and non-hospice) when there is a good penetration of hospice patients in the facility.

IDENTIFYING APPROPRIATE PATIENTS

Long term care facilities have lagged behind other health care entities in transitioning from paper documentation to an electronic medical record (Abramson, Edwards, Silver, and Kaushal, 2014). EMRs can be programmed with algorithms to quickly identify patients who meet pre-selected criteria for palliative care consults. Documenting on paper can make this identification challenging. Even if a facility has an EMR, outside agencies who are providing the palliative care services often do not have full access to data sharing with the nursing home.

The following are tools for identifying patients who may be appropriate for a palliative care consult in a nursing home.

The Palliative Performance Scale. This scale which was first introduced in 1996 has been proven to be a reliable tool (Ho, Lau, Downing, and Lesperance, 2008). While developed initially for the oncology world the tool has been validated as an effective tool for non-cancer patients as well (Harold, Rickerson, Carroll, McGrath, Morales, Kapo, and Casarett, 2005). One nursing home utilized the palliative performance scale in conjunction with their MDS assessment and used 30% as a threshold on the PPS to establish goals of care discussions which served as a precursor to a palliative consult (http://www.palliativealliance.ca/assets/files/Alliance_Reources/Physical_Care/PPS._edited_Jan_242013.pdf). This is something that could easily be built into rounding on patients, added to the MDS, or brought up at individual care conferences in identifying patients who are appropriate for at least a palliative consult.

Four-fold Combination. There are four domains that can easily indicate the need for a palliative consult.

1. The first is a positive response to the surprise question: "Would I be surprised if this patient does not live beyond a year's time frame?"
2. The second calls for communicating with the local hospital system where palliative care is offered to make sure that the nursing home knows when one of its patients received a palliative care inpatient consult.
3. The third strategy involves identifying patients who have had two or more hospital admissions within the last 6 months.
4. The fourth and final strategy, involves tracking any patients in the LTC facility who do not have documented goals of care in their chart. Developing a plan to identify these patients in conjunction with the nursing home will likely prove promising in initiating palliative consults.

MIDOS. The MIDOS or Minimal Documentation System has German origins and is similar to the Edmonton Symptom Scale, which has its origins in oncology. The MIDOS is a validated assessment tool (Weissman and Meier, 2011). The MIDOS was designed to identify potential palliative care patients. It has been studied specifically with dementia patients and found effective in indentifying patients from that population who could benefit from palliative care. It is a single one page symptom assessment tool (Baker, Luce, and Bosslet, 2015).

Flacker Mortality Scale. The Flacker Mortality Scale helps identify patients who are at a high risk of dying in a one year time frame. Some of the scoring is derived from the MDS assessment. Here is where it can be accessed: http://www.ucdenver.edu/academics/colleges/med-icalschool/departments/medicine/hcpr/palliativecare/mortalitytools/Documents/Flacker%20Mortality%20Score.pdf

RAI-PC. The Resident Assessment Instrument for Palliative Care or RAI-PC is part of the InterRAI collaboration of assessment tools. The InterRAI was designed specifically for residential patients to assess for a variety of items relative to medical, rehabilitation, and support needs of a patient. The RAI-PC is designed to be used in a variety of settings, including nursing homes, community, and acute care settings.

There is a subset of the RAI-PC with fewer questions that indicate a specific need for hospice care. The RAI-PC is a standardized comprehensive assessment tool to help identify patients who would benefit from a palliative care intervention. A number of peer-reviewed journal articles have been written touting the effectiveness of the tool. You can access information regarding the RAI-PC from: http://www.interrai.org/palliative-care.html

POTENTIAL STRATEGIES

There is clearly a great need for palliative care in nursing homes. Therefore, it is critical to have tools to identify patients for both an initial palliative care consult as well as follow-up treatment. How does one collaborate with a long term care facility in order to accomplish this goal? Recognizing the need is one thing; integrating palliative care into a long term care facility is another.   Often, it is an outside agency (hospice and/or palliative care) trying to make the case to the nursing home administration that palliative care services are needed within the walls of the facility. Here are some steps to consider:

▌ Meet with the MDS Coordinator, facility Director of Nursing, and administrator to identify gaps, needs, and ways to collaborate.   Share peer-reviewed literature on palliative care in nursing homes. Examining hospital readmission patterns among nursing home patients, the Five Star Medicare Quality Rating, existing hospice average and median length of stay statistics at the facility, and internal pain scores can help make the initial case for the implementation of palliative care. The facility will need to understand "what's in it for them?"
▌ Design a nursing home palliative care team, carefully looking at construct, scope, quality metrics, volume forecasting, financials, and overall return on investment.
▌ Ask to pilot in a small facility which is part of a larger chain or in one or two nursing units in a larger nursing home.
▌ Agree to data share relative to hospitalizations, transitions to hospice, pain scores, and other quality metrics.
▌ Decide which indicator(s) you will use in collaboration with the facility to identify palliative-appropriate patients.
▌ Assess results monthly, quarterly, etc. to ensure goals are being accomplished.
▌ Expand services. Once success has been achieved in a pilot program (i.e., a small nursing home or multiple nursing units) then begin "telling your story" to other facilities and gradually expand your footprint, increasing palliative staffing along the way.

The objective in using indicators is to move palliative care further upstream. It seems that there is still a mindset that palliative care is just a brief precursor to hospice care. However, while palliative consults will often lead to goals of care discussions and ultimately hospice enrollment, palliative care for nursing home patients offers so much more. Increasing quality of life by reducing unnecessary hospitalizations, providing effective pain and symptom management, and giving overall whole-person care are truly hallmarks of palliative care.

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