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Assessing Palliative Care Needs in Residents with Alzheimer's Disease

Emily Yarnell

Executive Summary

Introduction of the Problem

The Alzheimer's Association (2017) reports that more than 5 million Americans are living with Alzheimer's disease. Alzheimer's disease and other dementias rank as the 6th leading cause of death in the United States and one in three seniors die of the disease (Alzheimer's Association 2017). Efforts to effectively care for patients with Alzheimer's disease are essential to improve the quality of their end of life care. This project was to improve end of life care by implementing a research-based palliative care assessment protocol for patients with Alzheimer's disease in one facility.

A skilled Alzheimer's assisted living facility in Southern Illinois was selected for the implementation of this project. The nurses at this facility focus primarily on function of persons with Alzheimer's disease. However, assessments focusing on palliative care needs such as pain and physical deterioration are lacking. This gap in practice supported the need to collaborate with advance practice nurses and physicians to implement an assessment for early identification for palliative care.

Literature Review

Evidence suggests that advanced care planning for the end of life aids in providing holistic care to patients when the outcome of death is inevitable. Patients with Alzheimer's disease is one example (Ahronheim, Morrison, Morris, Baskin, & Meier, 2000; Sampson et al., 2011). The low occurrence of advanced care planning for palliative care in this population subset may be due to negative attitudes towards death and/or, Alzheimer's disease (De Vleminck et al., 2014). Assessing for palliative care needs in this population enables nurses to provide holistic care through all stages of the disease process (Campbell et al., 2016; Turton, Williams, Burton, & Williams, 2018). The goal is to have a palliative care plan before the patient is actively dying. Using palliative care approaches for symptoms of advanced dementia can reduce symptom burden and improve quality of life for patients and their caregivers (Zahradnik, & Grossman, 2014).

The World Health Organization (WHO) considers palliative care to be "an approach that improves the quality of life of patients and their families through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002, p. 24). Furthermore, palliative care services greatly reduce the cost of hospital admissions and the risk of a hospital death among patients with Alzheimer's disease (Miller et al., 2012; Currow et al., 2015; Meier, 2011).

Project Methods

The primary aim of this project was to implement a palliative care needs assessment tool to be used in a skilled Alzheimer's assisted living facility in southern Illinois. This assessment tool aids in the identification and initiation of a palliative care consult for Alzheimer's residents in this facility. The Global Deterioration Scale (GDS) by Reisberg, Ferris, de Leon, and Crook, (1982) was currently being used at the assisted living facility of this project to assess the patient's level of dementia. The residents are assessed with the GDS upon admission and then reassessed again on a yearly basis. During the time of project implementation, the resident's GDS score that was already in the chart was used to determine an accurate placement on the Dementia Progression Prioritization of Goals model (van der Steen et al., 2014). According to

this model, maximization of comfort is the goal for patients in the moderate to severe dementia stages (van der Steen et al., 2014). This is the part of the decisional aid that will help determine if the resident qualifies for a palliative care referral to the primary care physician.

The project was implemented at a skilled Alzheimer's assisted living facility in Southern Illinois. There is a total of up to 36 residents, all with a diagnosis of Alzheimer's disease or another form of dementia. The facility has 3 assisted living houses with up to 12 residents in each house. There is one nurse for each house of approximately 12 residents. A primary care physician, the project's stakeholder, and a total of 10 nurses were involved in the education and implementation of this assessment tool. The implementation period consisted of 10 weeks to allow sufficient time to assess a minimum of 20 residents. Educational sessions were held for the health care providers and an evaluation survey using a Likert scale was completed by the participants after the education session to evaluate their perspectives on how feasible the screening tool would be in their daily practice. Survey data results were reported in aggregate form to the stakeholder to identify and address potential barriers that are perceived by the staff for implementation of this palliative care assessment protocol. Project implementation also consisted of chart reviews to assess how many of the screened residents qualified for a palliative care consult according to their GDS score and where it fit in the Dementia Progression Prioritization of Goals model. Of those whose score was suggestive of maximization of comfort, further review of the chart was done to evaluate if a palliative consult was already in place with the previous practice of only using the GDS. When a need for a palliative care consult was identified, communication of this need with the primary care physician was initiated for a potential referral for a palliative care consult. IRB approval was obtained prior to implementation of this project.

Evaluation

A PowerPoint presentation was presented to a total of ten RNs and LPNs. Three different education sessions were offered to fit all of the nurses work schedules. Education included explanation of the implementation process for the palliative care assessment protocol and the specific number of patients per house with each GDS score obtained from the chart reviews. The findings from chart reviews indicated that a shocking 27 out of 31 residents were at a GDS score of 5 or greater which indicates the maximization of comfort goal. Of those 27 residents, only 10 had active palliative care plans. For the 17 residents who did not have an active palliative care plan, the primary care physician was contacted to evaluate the potential for a palliative care referral.

The presentation lasted approximately 15-20 minutes followed by a brief period of questions and answers. After the educational session, each participant completed an evaluation survey, which included a 5 question Likert scale questionnaire and 2 open ended questions. A total of ten evaluation surveys were completed. The survey questions focused on identifying areas of improvement, assess overall understanding, and provider perceptions about the feasibility of implementing this protocol in their daily work. The overall results of the Likert scale survey showed that staff were in agreeance that they understood the process and steps of the proposed palliative care assessment protocol that was presented. Eighty percent of the staff agreed that the tool would be useful in providing an accurate assessment for palliative care needs. On the other hand, 10% neither agreed nor disagreed and 10% disagreed the tool would be useful in providing an accurate assessment for palliative care needs. Staff were in agreeance the palliative care assessment protocol would be feasible to use within their daily practice and that it could be helpful to the care of their patients.

The two open ended questions focused on asking the staff to discuss what they liked about the palliative care assessment process and to suggest any possible changes that could be made for the palliative care assessment protocol to be successful. Fifty percent of the staff thought that the palliative care assessment process was simple. Twenty percent said the palliative care assessment process would help them initiate future palliative care consults. Furthermore, the staff expressed that there are many residents at the facility with a GDS score of 4 or 5 who would not need palliative care. Staff suggested placing patients with a GDS score of 4 or 5 in the maintenance of function group instead of the maximization of comfort group. The open-ended questions failed to prompt staff to provide further suggestions and ideas.

Impact on Practice

This project aimed to develop and implement a palliative care assessment protocol to be utilized in an Alzheimer's skilled facility. The immediate impact of this project was that after education about the protocol, the nurses perceived they could be able to successfully use the palliative care assessment protocol in their daily practice to determine if the patient needs a palliative care evaluation. Out of the 17 residents needing a palliative care plan, to date, 4 were admitted to hospice and have recently passed and 4 more received palliative care plans. Limitations include a small sample size and only a single facility utilized for implementation. In the open-ended evaluation, nurses expressed concern about being able to adjust the protocol. For example, many residents at the facility have a GDS score of 5 which would put them in the maximization of comfort goal. Some nurses thought this GDS score was too low to initiate a palliative care consult. They believed that most of the GDS 5 residents should belong in the maintenance of function group. Further follow up would be needed to explore the reasons staff felt that these patients did not need palliative care. Based on the information provided by the

staff, further explanation of the research evidence with rationales of the importance of initiating palliative care at a GDS score of 4 or 5 would be important. Other evidence-based assessment tools could also be explored if they might be more feasible to use in conjunction with the GDS. Long-term follow up would be needed to better evaluate patient outcomes at this facility as a result of using the assessment tool. This project could also be replicated on an even larger scope expanding to more than one facility and expanding the sample size.

Conclusion

The results of this project suggest that the palliative care assessment protocol is easy to use and could be beneficial to practice. Providing education to nurses, in a skilled Alzheimer's facility, about the importance of assessing for palliative care needs is essential when caring for this patient population. Having a progressive and life limiting disease does not deny the patient the right to dignified quality end of life care. Possible modifications to this project may include adjusting the GDS scores to the prioritization of goals.

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