

BENEFITS OF EARLY HOSPICE REFERRAL: A FAMILY EVALUATION

By

JESSICA JENSEN

A project submitted in partial fulfillment of
The requirements for the degree of:

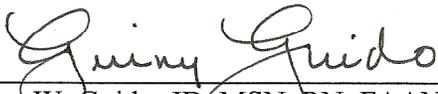
MASTER OF NURSING

WASHINGTON STATE UNIVERSITY
College of Nursing

MAY 2013

To the Faculty of Washington State University:

The members of the Committee appointed to examine the project of
JESSICA JENSEN find it satisfactory and recommend that it be accepted.



Ginny W. Guido, JD, MSN, RN, FAAN, Chair



Renee Hoeksel, PhD, RN



Janet Spuck, MS, RN

BENEFITS OF EARLY HOSPICE REFERRAL: A FAMILY EVALUATION

Abstract

Jessica Jensen
Washington State University
May 2013

Chair: Dr. Ginny Guido

This paper examines the evidence for the benefits of early hospice referral on the family caregivers of terminally ill adults. Specifically, the following benefits of timely referrals are examined: satisfaction with hospice services, emotional/spiritual support, and physical impact. These topics are then integrated into how they affect the role of the advanced practice nurse (APRN) and guidelines are provided for these practitioners as many times care of these patients is co-managed with a specialist and the primary care provider. It is recommended that patients utilize hospice services for at least 3 months in order to benefit from the psychological and physical support hospice provides (Schockett, Teno, Miller & Stuart, 2005). Despite these recommendations, many patients still receive late referrals, defined as a hospice stay of less than or equal to 21 days (Schockett et al., 2005) and may not fully benefit from the services offered through hospice. Benefits of early hospice enrollment include increased satisfaction with hospice services and increased emotional and physical support during the patient's dying process and bereavement period.

Table of Contents

Abstract	iii
Case Study	1
Introduction	1
Purpose of the Paper	3
Theoretical Framework	3
Literature Search Strategies.....	5
Literature Review	5
Significance to Nursing.....	12
Conclusion.....	15

BENEFITS OF EARLY HOSPICE REFERRAL: A FAMILY EVALUATION

Case Study

The initial setting is hopeful and curative for a 45-year-old female diagnosed with early stage breast cancer who had achieved remission for several years; unfortunately the disease progression was noted years later with bone and brain metastasis. With a grim survival prognosis, aggressive treatments were still pursued that included: whole brain radiation, renal dialysis, and parenteral nutrition due to weakness and decreased oral intake. Her hospitalization was extensive, with the patient staying 42 days. Despite the obvious signs of physical decompensation, the family continued to pursue aggressive treatments and end-of-life care plans were rarely discussed in family care planning. With the patient being unable to discuss care plans for herself, as the brain metastasis had affected her speech and thought processes, her husband was left to make these incredible and unimaginable decisions for his wife's future. Not wanting to give up hope for his wife and their children, yet not making progress or addressing the inevitable concerns of end of life planning, this relatively young woman was placed in hospice care three days before her death.

During the duration of her aggressive care, the family was focused on the patient's quantitative indicators such as laboratory values, vital signs, and mobility improvements. Quality of time and depth of meaningful conversations and memorable moments that her children, husband, and friends could cherish forever were lost and replaced with mundane meaningless figures that in the end stole precious and limited moments for family connection.

Introduction

The stress of caring for a family member with a terminal illness is taxing not only during the treatment phase, but also as the loved one prepares to die. The initial and terminal phases of

care create the most stress for family caregivers (Gaugler, et al., 2005). These untrained individuals provide extensive physical, emotional, and financial support to ill persons (Bevans, 2012). Family caregivers provide demanding care for terminally ill patients, which impact the caregiver's quality of life (Chiu, 2010). As the amount of medical resources decreases and more services are provided in an outpatient setting, family and friends are expected to care for patients in the home with many demands placed on them to ensure that quality and consistent physical and emotional care are provided (Mosher, Bakas & Champion, 2013). It is estimated that 68.6% of hospice patients receive care from a family caregiver (National Hospice and Palliative Care Organization [NHPCO], 2010). With significant care responsibility placed onto family and friends, it is of interest to providers to assess if hospice referrals are being made in a timely manner in order to ensure families are receiving the benefits of hospice.

Hospice is defined as care given to patients with life limiting illness that focuses on family support, symptom management, and patient comfort (NHPCO, 2012). It is recommended that patients utilize hospice services for at least 3 months in order to benefit from the psychological and physical support hospice provides (Schockett, Teno, Miller & Stuart, 2005). Referrals need to be made in a timely manner in order to minimize the stress during the transition to hospice care and increase family support. Despite these recommendations, many patients still receive late referrals, defined as a hospice stay of less than or equal to 21 days (Schockett et al., 2005) and may not fully benefit from the services offered through hospice. It is important to evaluate the support for hospice enrollment not only as a benefit for the patient, but also the families during this difficult transition.

The NHPCO reported 35.3% of patients died or were discharged within 7 days of admission to hospice (NHPCO, 2012). This short admission time resulted in missed

opportunities for effective family education, symptom management, spiritual support, and grief work. Though the NHPCO (2012) estimated 41.9% of deaths in the United States occurred in persons receiving hospice services, these services are not being used in a timely manner in order for patients and families to fully benefit from the referral (Schockett et al., 2005). Development of guidelines for hospice referral for family nurse practitioners will enhance their ability to refer patients and families to this service in a timely manner.

Purpose of the Paper

Nurse practitioners need to begin to ensure timely and appropriate referral of individuals who qualify for hospice service in order to minimize negative physical and emotional effects on the family caregiver. The progression and trajectory of end of life care greatly influences the experience of the caregiver and subsequently his or her quality of life after the death of the family member (Penrod, Hupcey, Shipley, Loeb & Baney, 2011). The purpose of this paper is to examine the evidence for the benefits of early hospice referral on the family caregivers of terminally ill adults. Specifically, the following three benefits of timely referrals will be examined: satisfaction with hospice services, emotional/spiritual support, and physical impact. These topics will then be integrated into how they affect the role of the advanced practice nurse (APRN) and guidelines will be provided for these practitioners as many times care of these patients is co-managed with a specialist and the primary care provider during the duration and terminal part of the patient's illness.

Theoretical Framework

The grounded theory, Model of Caregiving Through the End of Life, provides a lens for placing hospice care into the framework of caregiving transitions, which can guide health care providers in providing care to the caregivers of terminally ill patients. The model describes

family caregiving as a continuum of phases and transitions. Four phases are identified: (a.) sensing a disruption, (b.) challenging normal, (c.) building a new normal, and (d.) reestablishing a new normal. Recognizing this theory of “illness and dying as a complex, longitudinal experience with recognizable phases promotes more coherent planning for service delivery” (Penrod et al., 2011, p.8). This allows the caregiver’s role in hospice to be viewed as an integral part of illness management that has long lasting effects for the caregiver as they begin to reestablish a new norm after their loved one has died.

The rapid transition to hospice services also warrants evaluation as to how it affects the caregivers’ cognitive structure as the movements between care modalities change. As each caregiver travels through the continuum, providers need to implement patient centered interventions, which are stage specific in order to effectively assess and intervene during each unique stage. It is pivotal that all phases of the caregiving transition, from pre-diagnosis to end of life care, are accounted for as they shape the family’s experience of terminal care and health viewed holistically thereafter (Penrod et al., 2011).

As family members begin to re-establish a new norm, it is vital they have a positive experience with hospice and bereavement services, as the probability of future exposure to hospice is high with the aging population. Creating an awareness of the negative effects late hospice enrollment can have on families will ensure more of a team approach to hospice referral. Providing more data regarding the benefits of early hospice enrollment for families will assist providers in earlier referral, which can increase satisfaction with hospice services and decrease the probability of ill effects of late hospice enrollment on family caregivers.

Literature Search Strategies

The literature review was conducted via the Washington State online library. Key word searches on PubMed included “ hospice satisfaction and families.” Limiters of articles included published within the last five years, peer reviewed, and that the subjects in review were adult patients. Search results yielded 89 articles, six were reviewed and four were chosen. Further PubMed searches using key words “late enrollment and hospice,” “late referral to hospice,” and “benefits of hospice referral” produced 78 articles, of which 15 were reviewed and six were chosen.

PsychINFO was searched using terms “hospice and family and late referrals.” Twelve articles were found, three were reviewed and one was used. Limiters included articles published after 2003; peer reviewed, and contained data on adults.

Literature Review

In order to fully assess the benefit of hospice enrollment has on family caregivers, it is crucial that hospice satisfaction, emotional support, and physical impact are evaluated. The above three themes are reviewed in the following sections of this literature review.

Hospice Satisfaction

Satisfaction with hospice services is at the heart of hospice philosophy as it serves to personalize care and support families. Identifying themes that are associated with increased satisfaction is important in establishing what services and time frames are most effective in delivering care. Satisfaction surveys from family members given at one and three months into bereavement, with results obtained from over 800 different hospices around the United States, Puerto Rico, and the District of Columbia, indicated several factors influencing family’s satisfaction with hospice care. Indicators based on the Family Evaluation of Hospice Care

(FEHC) questionnaire, included: attending to family's need for communication, emotional support, care coordination, and physical comfort all contributed to the family's overall satisfaction with hospice care (Rhodes, Mitchell, Miller, Connor & Teno, 2008). Based on this study with a large sample size (n= 116,974), the analysis performed via multivariate logistic regression noted if hospice providers were engaging in effective family communication, knew the patient's medical history, provided efficient care coordination and adequate symptom management, satisfaction results were four times higher than families who did not score these items positively. With the above qualities noted to increase satisfaction, it seems providing an adequate amount of enrollment time in the hospice program would allow for the most effective family education and engagement of care providers to meet the demands of these themes.

Establishing common themes that increase family satisfaction can be used to promote use of resources in these particular areas. Open-ended satisfaction surveys obtained from 100 family members whose family member died within seven days of hospice referral showed that two-thirds of these family members felt the patient was referred to hospice "too late." Additionally, the most dissatisfying aspect of hospice care for this cohort was lack of communication between staff and family (Teno, Casarett, Spence & Connor, 2012). Although many of these respondents noted an earlier referral was not possible, it seems that this short timeframe added to the lack of effective communication and greatly impacted the satisfaction of hospice care.

Utilizing the themes found in satisfaction surveys and correlating responses with enrollment time in the program provides insight into what themes are most important to families during each phase of terminal care. A quantitative and qualitative study, which interviewed families of subjects older than 65, enrolled in the Medicare hospice benefit, and had received hospice services for at least two weeks (n=120), 31.4% of respondents reported things would

have been easier if they had enrolled in hospice care sooner. Quantitative data were obtained from the hospice chart and qualitative data were obtained from a structured interview.

Demographics of the respondents who noted longer hospice enrollment as beneficial were more likely to be from lower income areas, have limited access to medical care, and be Medicaid recipients (Adams, Bader & Horn, 2009). Identifying high-risk families that would benefit from hospice support can also increase satisfaction and positive family outcomes through increased support services.

Additional hospice satisfaction surveys (response rate $n=237$) indicated that 13.7% of families perceive their family member was referred to hospice “too late.” Of the sample population 59.4% had cancer and of this subsection, the average hospice stay was 46.9 days. This was indicated as “too late” for this specific patient population. The perceived late referrals indicated less satisfaction with family education, confidence in hospice team coordination, and unmet emotional needs (Schockett et al., 2005). Although this study yielded results that indicated less satisfaction with hospice services with limited enrollment time, other studies have found the enrollment time does not directly correlate with satisfaction of services (Miceli & Mylod, 2003). This discrepancy in data reveals an area that needs further research in order to provide a definitive framework of what themes of care are most valued and increase satisfaction among families during each phase of terminal care.

Miceli and Mylod (2003), utilizing the Press Ganey Hospice Care Family Survey, evaluated perceptions of family’s feelings of the care delivered after their loved one had died. Satisfaction questionnaires were dispersed to 1,839 caregivers; 89% of these respondents indicated this was their first experience with hospice. For these same respondents 33% reported that the family member had received care for under a week, 30% received care for over a week

but less than a month, and 32% received care for over six months. Satisfaction results were rated using a Likert-type rating scale and the mail-in survey presented strong consistency and reliability of the survey methodology with reported Cronbach alphas of 0.99% for all questions and subscales. Based on these responses, issues that were most dissatisfying were related to logistical coordination, availability of staff, family education, and bereavement services. Issues that received high satisfaction scores included nursing care and coordination of care by a hospice physician (Miceli & Mylod, 2003). Identifying qualities that increase satisfaction in hospice care can be a mechanism to support and provide personal, more satisfying service to each hospice family.

Based on the above review of satisfaction indicators and beginning correlations of the themes with length of hospice use, the length of hospice enrollment was not directly correlated with increased satisfaction, but families who *believed* they were referred in a timely manner were strongly correlated with increased satisfaction with hospice services (Miceli & Mylod, 2003). Of the 70.9% of families indicating their family member was referred “too late,” these family members were enrolled 7 days or less. However, 27.4% of families indicated hospice referral at the “right time” when it was under seven days. While it is certain the perception of appropriate referral times varies, it is unlikely the optimal time is within a week of the patient’s death (Miceli & Mylod, 2003).

Although adequate time enrolled in hospice is ideal, satisfaction of families receiving care for less than the optimal times should be addressed to provide further insight into where the deficits of care are for this population. Further semi-structured interviews conducted during initial enrollment and at one month after the patient’s death reported a greater benefit of service with longer hospice enrollment; however, shorter stays also noted that the participants received

the anticipated services they expected from hospice, but had lower overall satisfaction (Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). These results were drawn from a sample population (n=275) in a single geographical location, first time hospice users, and those who spoke English. Findings noted an increase in services used with longer enrollment periods ($p < .001$) and higher mean helpfulness of services was associated with an increased length of stay ($p < .001$). Due to the selective enrollment criteria used in this study, results have limited generalizability. Nevertheless, insights from this study showed increased hospice time provided greater perceived benefits for families and more effective delivery of services.

Other benefits that can be attained from earlier enrollment are more individualized care for the family caregiver. In a qualitative comparison study, family caregivers enrolled in hospice identified primary, secondary and intrapsychic stressors, noting that practical support, validating the importance of the caregiver's role, and adequate education regarding pain management were the most distressing issues to families. The study also surmised that although hospice interventions seek to support and address these issues, their interventions were applied at a more global level and lacked individualization and thus were not viewed as helpful by families (Wittenberg-Lyles et al., 2012). Taking this into consideration, it is likely that if the family was enrolled in hospice for longer periods, more specific caregiver interventions could be applied thus providing superior support services.

Emotional Support

After caregivers have experienced a highly emotional and physically demanding event of caring for a terminal family member, the possibility of depression during the bereavement period becomes a concern. In a prospective longitudinal study of 174 family caregivers who were interviewed upon hospice admission and at six-eight months after the patient's death, major

depressive disorder (MDD) was assessed using the Structured Clinical Interview for the DSM-IV (SCID) axis I module and administered by a master's prepared social worker. Data analysis was completed using logistic regression to determine the association between MDD and length of hospice enrollment. Caregivers of patients with hospice enrollment less than 3 days were significantly more likely to have MDD on follow-up interview with 24.1% reporting depression compared to the 9% who were enrolled in hospice care longer than 3 days (unadjusted odds ratio=3.23, 95% confidence interval=1.16-8.99) (Bradley et al., 2004). These findings illustrate the emotional benefits derived from early hospice care.

An additional bereavement study utilizing numerical scales and the Geriatric Depression Scale (GDS) measured quality of end-of-life care and feelings of regret during bereavement of the 147 family members who filled out a mailed questionnaire. Results reached statistical significance in decreasing regret during bereavement on items such as quality in home care (Cronbach alpha 0.87), a peaceful death of the loved one (Cronbach alpha 0.92), and ability to provide direct care to the ill family member (Cronbach alpha 0.81) (Akiyama, Numata & Mikami, 2009). These results were further analyzed using one-way analysis of variance (ANOVA) to compare the different responses based on time since the patient's death. These results demonstrate that a timely referral to hospice care can greatly increase the ability of hospice staff to coordinate quality home services, physical comfort, and adequate family education. Effective education would not only support families in being intimately involved in patient care during the end of life, but also feel confident about the care they are providing. It is not only the support provided to the family in the initial periods of hospice referral, but also the continued benefits acquired during the bereavement period that provide further support for importance of early hospice enrollment.

Indicators of risks for complicated bereavement and subsequent psychiatric disorders such as MDD, post-traumatic stress disorder (PTSD), and complicated grief (CG) need to be identified early in the care of the family. Analysis of interviews of 122 bereaved persons at 4, 5, and 9 months after the death of their loved one indicated themes such as lack of preparedness and perception of death influence the rate of MDD and CG. Respondents had a 1.93 times greater rate of MDD with every one unit of lack of preparedness for death (Barry, Kasl & Prigerson, 2002). Given the negative psychiatric sequelae associated with lack of preparedness for death it is vital for families to have access to hospice services to mitigate the potential for this diagnosis and ensure future psychiatric health.

Physical Impact

Considering all the components of caregiving with the physical, emotional, and spiritual ramifications it is not surprising that there is a “widow/er’s effect” noted with many spouses dying during bereavement periods or shortly after. Data derived from the Medicare claims, coded for “care after the onset of serious illness” (COSI), which offers a large sample size to assess the mortality of spouses after the death of their partner, show an increase in mortality rate when a spouse died (Christakis & Iwashyna, 2003). This population matched retrospective cohort study, analyzing spouses of COSI claims, reported an increase in mortality for bereaved spouses whose partner did not receive hospice care during end of life (95% CI: 0.84–1.06) (Christakis & Iwashyna, 2003). This large sample (n= 195,553) and inclusion of an independent cohort for comparison demonstrated that spouses, particularly women, whose partner was enrolled in hospice for end of life care, had a decrease in mortality compared to the control group (those who did not receive hospice services). Hospice use for an average of 3-4 weeks was associated with a statistically significant benefit for the bereaved spouse (Christakis & Iwashyna, 2003). Based on these results, caregiver assessments and interventions should focus on potential risks

for complications during the bereavement period and a greater emphasis on earlier hospice enrollment to provide support to diminish these negative family caregiver physical effects.

Many times, when tending to patients in the home setting the amount of physical care that needs to be done directly by family members is substantial and can have negative physical ramifications for the caregiver. A survey of caregivers of end-stage Parkinson's disease patients that examined items that increased caregiver burden at end of life noted tasks involving physical effort as being the most distressing. Caregivers reported serious physical challenges in the areas of lifting and toileting patients. Survey respondents (n=47) were typically elderly, Caucasian female spouses with surveys distributed at a median of 18 months after the death of the patient; about half of the respondents were enrolled in hospice. Measurements included a numerical rating of medical care in the last 6 months of life and the Center Epidemiological Studies Depression Scale (CES-D) (Goy, Carter & Ganzini, 2008). Highly distressing issues related to the physical aspect of caregiving need to be considered and interventions implemented to assist in this difficult task in order for families to continue providing safe, effective, loving care in the home. Limitations of this study included a small homogenous sample size and the nonidentification of the amount of time patients were enrolled in hospice during the last six months of life. However, the basic concept that physical care is distressing to caregivers is a theme that can be investigated universally to establish interventions to aid families as they provide terminal care.

Significance to Nursing

Given the above findings of the effect end-of-life caregiving has on families, family nurse practitioners caring for patients are positioned in an ideal professional situation to intervene and discuss hospice care and potential referrals. It is noted that 31% of patients with advanced cancer

had not had a discussion of end of life care planning with their oncologists, however 60-70% of Americans are willing to discuss end of life care planning if they are asked by a provider (Zhou, Stoltzfus, Houldin, Parks & Swan, 2010). These data illustrate that there is lack of discussion and assessment of end of life care planning, which contributes to the disruption of family structure as seen with late hospice referral. Holistic nursing care is defined as assessing patient's mind, body, and spirit not just symptoms based on their diagnosis (Newson, 2007). Based on the definition of holistic nursing care, it is clear from the literature that rapid transition to hospice affects multiple aspects of families' health. Appropriate measures need to be implemented in order to screen family members for potentially negative side effects of caring for a terminally ill loved one and promote early hospice referral. Educating and including all providers in the assessment, plan, intervention, and evaluation allows for the appropriate services to be delivered to families in a timely manner.

Guidelines for Providers

Given the diverse and often complex multiple diagnoses that contribute to end of life care, it is vital that generalists such as family nurse practitioners have the information and ability to recognize and discuss hospice care philosophy with families to provide them with adequate information regarding this service. As technology advances, more aggressive treatment options are offered, and as the population ages, with estimates of 1 in 5 Americans will be over the age of 70 by 2030, a greater need for hospice care will arise within this country (Brooten, Youngblut, Hannan, & Guido-Sanz, 2012). Although malignancies are a common cause of hospice referral, the NHPCO reported 64.4% of patients in 2010 were admitted to hospice for non-cancer diagnosis and only 10 % of end stage heart failure patients actually enroll in hospice care (Zambroski, 2005). This places the PCP at the heart of managing care as specialists begin to

exhaust their curative treatments and the patient begins to decompensate.

Given the complexity of hospice transition it is valid to try and introduce the subject matter in a way that fosters support for families and highlights the benefits. Although this is a difficult conversation to have at any point of care knowing the benefits and support hospice has to offer, initiating this care option will provide a different outlook on terminal care for families and patients. Recognizing the potential benefits for families including the emotional and physical support that ultimately increases satisfaction with hospice care creates a referral that is based on easing the way into hospice care.

The Model of Caregiving Through the End of Life theory defines caregiving as a transition through many steps until a new norm is established (Penrod et al., 2011). As the literature revealed, this transition could consist of long lasting physical and emotional side effects. The Theory of Caregiving Through the End of Life illustrates that each phase consists of various transition points as the patient receives different treatments which will affect the caregiver's view of illness and cultivate different coping mechanisms through each phase. As providers who understand the transition periods and view caregivers as "coproviders" and "corecipients" of care more support can be designated during highly emotional and vulnerable points during end of life care (Penrod et al., 2011).

The family nurse practitioners involvement in hospice referral can occur at several levels while caring for these complex patients and their families to minimize and ease the transition to end-of-life by (a.) assessing and evaluating the family structure and patient's willingness for hospice care(b.) discussing the benefits and care philosophy of hospice during a course of illness both chronic and acute if deemed necessary (c.) having access to community hospice programs

to refer patients and families when appropriate. Creating these relationships and having an open line of communication with terminal patients will allow them to more freely choose between the most appropriate care option in the end of their life.

The family nurse practitioner may be involved in managing terminal patients with specialists and often need to address the option of hospice care as part of the treatment options in order for the patient to have the correct information about all available treatments. Given the relationships that are created in primary care, often patients and the provider have a close relationship and the conversation of end-of-life care is most appropriate in this setting. This close relationship provides an ideal opportunity to assess the family's needs and discuss future plans of care. Incorporation of the theoretical framework “ opens the door for discussions of the expected nature of terminal decline and end-of-life preferences”(Penrod et al., 2011, p. 17). Ideally this proactive conversation and introduction of hospice services can be delivered early in the diagnosis of terminal illness while in the phase of “challenging normal.” Integrating and recognizing these phases of end-of-life care will provide a faster, more cohesive transition to hospice care, which in turn will assist families in managing and providing care to their loved one.

Conclusion

As family members begin to re-establish a new norm, it is vital they have a positive experience with hospice and bereavement services, as the probability of future hospice exposure is high. Creating a team approach to hospice referral and management will provide for more appropriate hospice referrals and subsequent positive outcomes for family caregivers. Early recognition of chronic conditions, which may turn terminal, is at the crux of providing early intervention and education about hospice and care delivered through this service. Because of the complexity of discussing end of life issues many patients enter the health care system unaware of

their personal choices if this topic is never addressed by their providers (Chrash, Mulich & Patton, 2011). Integrating hospice care as a treatment option and having it discussed by all providers will also increase familiarity with the subject matter and promote patient and family participation in advanced care planning.

Familiarity and comfort while discussing this highly emotional care option will not only benefit providers in the ease of discussing this issue, but if the patients have been introduced to the concept early in their illness the option may seem less daunting. Incorporating holistic spiritual assessment in conjunction with advanced care planning prior to a crisis or emergent hospitalization is an ideal time to discuss future care plan management for medically complex patients (Chrash et al., 2011). As APRN's identifying, integrating, and discussing hospice as a care option for terminal patients provides a benefit not only to patient, but also to their caregivers. Given the positive association with hospice satisfaction, emotional and bereavement support, and physical burden that can be minimized with hospice provides clear motivators to have the discussion of care with patients before the timeframe has lapsed for them to benefit from the services. As a PCP treating and viewing families as a holistic unit, the transition and incorporation of hospice services into practice is a natural progression of care for these terminal patients and their families. Considering the growing number of patient's enrolled in hospice and the noted benefits of hospice care on families it proves to be not only an intimate issue at hand concerning the terminal patient, but also has broader implications for healthcare services as the benefits extend to spouses and caregivers (Ahrens, 2005). It is not only a professional responsibility to seek out the most appropriate treatments for caring for this complex population, but also a privilege to ensure the most support be given to the dedicated, hard working, selfless caregivers that aid these patients through their most vulnerable points in life.

References:

- Adams, C., Bader, J. & Horn, K. (2009). Timing of Hospice referral: Assessing Satisfaction While the Patient Receives Hospice Services, *Home Health Care Management Practice*, 1 (21), 109. doi: 10.1177/1084822308323440
- Ahrens, J. (2005). The Positive Impact of Hospice Care on the Surviving Spouse, *Home Healthcare Nurse*, 23 (1), 53-55.
- Akiyama, A., Numata K. & Mikami, H. (2009). Importance of end-of-life support to minimize caregiver's regret during bereavement of the elderly for better subsequent adaptation to bereavement, *Archives of Gerontology and Geriatrics*, 50, 175-178. doi:10.1016/j.archger.2009.03.006
- Barry, L., Kasl, S. & Prigerson, H. (2002). Psychiatric Disorders Among Bereaved Persons The role of Perceived Circumstances of Death and Preparedness for Death, *American Journal of Psychiatry*, 10 (4), 447-457.
- Bevans, M. & Sternberg, E. (2012). Caregiving Burden, Stress, and Health Effects Among Family Caregivers of Adult Cancer Patients. *Journal of the American Medical Association*, 307 (4), 398- 403.
- Bradley, E. H., Prigerson, H., Carlson, M., Cherlin, E., Johnson-Hurzeler, R. & Kasl, S.V. (2004). Depression Among Surviving Caregivers: Does length of hospice enrollment matter? *American Journal of Psychiatry*, 161 (12), 2257–2262.
- Brooten, D., Youngblut, J., Hannan, J. & Guido-Sanz, F. (2012). The Impact of Interprofessional Collaboration on the Effectiveness, Significance, and Future of Advanced Practice Registered Nurses, *Nursing Clinics of North America*, 47, 283–294.
- Chiu, Y. W., Huang, C. T., Yin, S. M., Huang, Y. C., Chien, C. H., & Chuang, H. Y. (2010).

- Determinants of complicated grief in caregivers who cared for terminal cancer patients. *Supportive Care in Cancer*, 18 (10), 1321-1327. doi: 10.1007/s00520-009-0756-6.
- Chrash, M., Mulich, B. & Patton, C. (2011). The APN Role in Holistic Assessment and Integration of Spiritual Assessment for Advance Care Planning, *Journal of the American Academy of Nurse Practitioners*, 23, 530-536. doi: 10.1111/j.1745-7599.2011.00644.xd
- Christakis, N. A. & Iwashyna, T.J. (2003). The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses. *Social Science & Medicine*, 57, 465–475.
- Gaugler, J., Hanna, N., Linder, J., Given, C., Tolbert, V., Kataria, R. & Regine, W. (2005). Cancer Caregiving and Subjective Stress: A Multi-Site, Multi-Dimensional Analysis, *Psycho-Oncology*, 14, 771-785. DOI: 10.1002/pon.916.
- Goy, E., Carter, J. & Ganzini, L.(2008). Needs of Experiences of Caregivers for Family Members Dying with Parkinson Disease, *Journal of Palliative Care*, 24 (2), 69-75.
- Miceli, P.J. & Mylod, D.E. (2003). Satisfaction of families using end-of-life care: Current successes and challenges in the hospice industry, *American Journal of Hospice & Palliative Care*, 20, 360-370. DOI: 10.1177/10499091030200051
- Mosher, C., Bakas, T. & Champion, V. (2013). Physical Health, Mental Health, and Life Changes Among Family Caregivers of Patients With Lung Cancer. *Oncology Nursing Forum*, 40 (1), 53-61. DOI: 10.1188/13.ONF.53-61.
- National Hospice and Palliative Care Organization. (2010). NHPCO facts and figures: Hospice care in America. Alexandria,VA: Author.
- National Hospice and Palliative Care Organization (2012). NHPCO Facts and Figures: Hospice

- Care in America. Retrieved from
<http://www.nhpco.org/i4a/pages/index.cfm?pageid=5994>.
- Newson, P. (2007). Thinking about Spiritual Care. *Nursing & Residential Care*, 9 (6), 246–249
- Penrod, J., Hupcey, J., Shipley, P., Loeb, S. & Baney, B. (2011). A Model of Caregiving Through the End of Life: Seeking Normal, *Western Journal of Nursing Research*, 20 (10), 1-20. DOI: 10.1177/0193945911400920
- Rhodes, R., Mitchell, S., Miller, S., Connor, S. & Teno, J (2008). Bereaved Family Members' Evaluation of Hospice Care: What Factors Influence Overall Satisfaction with Services?, *Journal of Pain and Symptom Management*, 35, 365-371.
doi:10.1016/j.jpainsymman.2007.12.004
- Rickerson, E., Harrold, J., Kapo, J., Carroll, J.T. & Casarett, D. (2005). Timing of Hospice Referral and Families' Perceptions of Services: Are Earlier Hospice Referrals Better? *Journal of the American Geriatrics Society*, DOI: 10.1111/j.1532-5415.2005.53259.x.
- Schockett, E. R., Teno, J. M., Miller, S. C., & Stuart, B. (2005). Late referral to hospice and bereaved family member perception of quality of end-of-life care. *Journal of Pain and Symptom Management*, 30 (5), 400-407. doi: 10.1016/j.jpainsymman.2005.04.013
- Teno, J., Casarett, D., Spence., C. & Connor, S. (2012). It Is “Too Late” or Is It? Bereaved Family Members Perceptions of Hospice Referral When Their Family Member Was on Hospice for Seven Days or Less, *Journal for Pain and Symptom Management*, 43, 732-738. doi:10.1016/j.jpainsymman.2011.05.012.
- Wittenberg-Lyles, E., Dermiris, G., Oliver, D., Washington, K., Burt, S. & Shaunfield, S. (2012).

Stress Variance Among Informal Hospice Caregivers, *Qualitative Health Research*, 22 (8), 1114-1125, DOI: 10.1177/1049732312448543

Zambroski, C. (2005). Hospice as an Alternative Model of Care for Older Patients With End-Stage Heart Failure, *Journal of Cardiovascular Nursing*, 19 (1), 76-83.

Zhou, Stoltzfus, Houldin, Parks & Swan. (2010). Knowledge, Attitudes, and Practice Behaviors of Oncology Advanced Practice Nurses Regarding Advanced Care Planning for Patients With Cancer, *Oncology Nursing Forum*, 37 (6), DOI: 10.1188/10.ONF.E400-E410