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The Effect of the Timing of a Hospice Referral and the Perceived Quality of Care by the Family

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Abstract

Hospice care is a specialized type of palliative care for patients with a time-limiting illness. Despite its benefits, hospice remains underutilized. A key reason behind the underutilization are untimely referrals, often made during the last weeks or days of the patient's life. The purpose of this paper is to investigate the existing barriers towards hospice that play into late referrals and its effect on patient/family satisfaction. This information will be examined to propose a pilot research study for further exploration.

Key Terms: hospice, timely referral, family satisfaction, underutilization, length of stay, barriers

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Introduction

Hospice care was created in 1974 to provide end of life care to the terminally ill person during the final stages of their life. It is eligible to any person with a six-month or less life expectancy. Rather than chasing a cure, hospice is a special kind of medical care that focuses on the quality of the client's life. Services of hospice include pain and symptom management, respite care for family members, and other palliative care services. Their purpose is not to hasten death, but rather to accept death as the final stage of life and to alleviate the sufferings of a client who is in the end stages of their disease so that they may spend their last days with dignity and comfort, surrounded by their loved ones.

Despite its benefits, hospice remains underutilized. The National Hospice and Palliative Care Organization (NHPCO) recommend that clients receive a minimum of 90 days in hospice to provide optimal multidimensional end-of-life care. In contrast to the ideal 90-day hospice stay, the median hospice stay is approximately 24 days (NHPCO, 2019). Short durations do not give the interdisciplinary team time to provide the maximum benefits of hospice and often result in unmet needs and dissatisfaction (NHPCO, 2019). A key reason behind the underuse of hospice is the late timing of referrals, often made within the last weeks or days of life.

There have been several studies in the last decade looking at factors that serve as barriers towards the timing of hospice referrals, as well as studies correlating hospice duration stays with patient and family satisfaction. These studies often reiterate the same theme — the sooner the patient is enrolled in hospice, the better the outcomes for the patient and their families tend to be. This, however, is often not the case. This paper aims to delve deeper into the existing barriers towards hospice that play into late referrals and its effect on patient/family satisfaction. In turn, the researcher hypothesizes longer hospice stays are associated with higher perceived quality of

care by both the client and their families. Furthermore, the researcher hypothesizes a higher level of satisfaction if the hospice care is received at home rather than in a facility.

Problem Statement

Patients who are in the dying process often suffer from severe pain, anxiety and depression, among other symptoms unique to their disease. Considered the model for quality compassionate care for people facing a life-limiting illness, hospice allows for the alleviation of these symptoms by assisting the patient and their families with around the clock nursing care, symptom management, medication maintenance, medical equipment, assistance with daily care and activities of daily living, spiritual support, counseling and bereavement services. Hospice care is available in a variety of settings such as hospitals, nursing homes, assisted living facilities, dedicated hospice facilities — however, most of the care is provided in the comfort of the patient's home (Mayo Clinic, 2019).

It is believed that there is a positive correlation between the length of hospice stays and patient/family outcomes (NHPCO, 2019). This is based on the idea that hospice decreases the burden on the family by providing respite care, while allowing for all members involved to prepare for the patient's death (decreasing the likelihood of complicated grief). However, according to a 2018 report from National Hospice and Palliative Care Organization (NHPCO), 40.5% of patients received care for 14 days or less, with those experiencing less than a week at 27.8%. Patients who had a principle diagnosis of dementia had the longest average stay of 110 days while patients with chronic kidney disease and cancer had the shortest average stay of 43 days (NHPCO, 2018).

Barriers that serve towards the underutilization of hospice care are include lack of education by both the patients, their families, and physicians. Deficient knowledge feeds into the

stigmas against hospice care where individuals are in denial about accepting hospice care because they equate it with giving up. Another possible barrier could be racial disparities, as 82.5% of patients receiving hospice care identify as Caucasian (NHPCO, 2018). This poses a major problem, as minority groups are often at higher risk for acquiring illnesses and often receive a lower quality of care (Kumar et al., 2016). Additionally, financial constraints may play a role into the utilization of hospice care. Currently, Medicare, Medicaid, the Department of Veterans Affairs are responsible for the costs of hospice with Medicare taking the bulk of the bill. Due to high costs, Medicare seems to be cracking down on hospice enrollments (Health Affairs, 2012).

Ultimately, health care providers need to improve communications with clients so that they are knowledgeable about their options and are able to receive optimal care and reach better, more well managed outcomes.

Purpose Statement

This paper aims to delve deeper into the existing barriers towards hospice that play into late referrals and its effect on patient/family satisfaction. In turn, the researcher hypothesizes longer hospice stays are associated with higher perceived quality of care by both the client and their families. Furthermore, the researcher hypothesizes a higher level of satisfaction if the hospice care is received at home rather than in a facility.

Research Question

How do experienced oncology nurses describe barriers to the timing of a hospice referral? Once a hospice referral is made, how do experienced oncology nurses describe the barriers the family face in implementing hospice care?

Theoretical Framework

The Human to Human Relationship Model of Nursing (Interpersonal Aspects of Nursing, Travelbee, 1961), developed by Joyce Travelbee, is the model used to examine the concept of patient/family satisfaction with hospice care. The main concepts behind this model are suffering, meaning, nursing, hope, communications, self-therapy, and a targeted intellectual approach. The role of nursing in Travelbee's theory is to guide the patient to find meaning in their experience of suffering, as well as to maintain hope. The Human to Human Relationship Model identifies the nurse-patient relationship as a critical component to successful patient care. This relationship is established by a five phase interaction processes driven by empathy and sympathy. The phases are: the original encounter; the visibility of personal or emerging identities; empathy; sympathy; and the establishment of mutual understanding and a rapport. Health is seen as both subjective and objective. Subjective health is an individually defined state of well being while objective health are based on measurable indicators of health.

Hospice care involves patients who are vulnerable to suffering and hopelessness. Establishing a nurse-patient relationship can lead to improvements of patients' physical, emotional, and spiritual conditions as well as facilitate acceptance of their fates, reduce their suffering, and eventually lead them towards a dignified death. However, when hospice stays are postponed, it may not give the interdisciplinary team sufficient time to meet needs, alleviate pain

and suffering appropriately, and strengthen emotional connections between patients and their families. Lack of trust, communication, empathy and sympathy leads to negative outcomes.

Literature Review

A literature review was conducted in order to provide the best, up to date evidence to support the need for timely referrals in hospice care. Articles were found using databases Iceberg and National Center for Biotechnology Information (NCBI). All articles reviewed have been published within 2014-2019. Publication of work listed in United States, Korea, and Japan.

Barriers to Hospice Utilization

From the Physician's Perspective. According to a study by Adams et. al (2009), physicians were identified as the most common (62.5%) barrier to “too late” hospice referrals.

Significant barriers affecting physician's timely referrals to hospice care included lack of standardized criteria for admission to hospice services, uncertainty of prognosis, discomfort in discussing prognosis (Spencer et al., 2017). Physicians often have a difficult time discerning when patient's have reached the “6 month prognosis,” and report postponing hospice discussions until they have sufficient evidence to accrue active treatment is no longer viable. “It is really, really hard to know when to stop. So what do you do, if you stop, and someone could have lived?” (Oncologist, 3-023, Spencer et al., 2017)

From the Patient's Perspective. Significant barriers affecting patients' acceptance of hospice care include cultural and ethnic barriers (Furka et al, 2014), socioeconomic status and accessibility to hospice services, deficient knowledge of what hospice is, and relocation stress related to discontinuity of care (Spencer et al., 2017). A retrospective review done by Furka et al. (2014) found that patients who declined hospice were predominately black (66%). Another qualitative-qualitative study by Adams et al. (2009) found patients/families

who reported it would have been easier if hospice services started early were predominantly Latino, living in lower income neighborhoods, and were enrolled in Medicaid. This may be related to the generalization that minorities prefer more aggressive treatments when compared to Caucasians, who, according to the authors, would rather have more aggressive pain and symptom management. This plays into a bigger issue of racial disparities within healthcare and POC lack of trust in the medical model and feeling as if they have to advocate for their own treatments. This barrier is further exacerbated by deficient knowledge of what hospice is, leading patients to equate hospice with giving up (Adams et. al, 2009).

Furthermore, relationships between patients and providers evolve overtime. Enrollment in hospice often severs these bonds and can be difficult for both parties. Patients may experience relocation stress when placed with a new health care team.

From an Organizational Perspective. Medicare is the greatest payer to hospice services and has influence on who is granted eligibility. A significant barrier to utilization of hospice seems to be the interpretation of its eligibility criteria. There is no standardized criteria for hospice, and relying on physicians' clinical judgement has poor sensitivity and specificity (Fine, 2018). Identifying consistent markers has been unsuccessful.

Furthermore, some medical treatments (e.g. dialysis) are viewed by providers as palliative but there are variations to which hospices allow these to occur. In some cases, the need to continue these treatments were the primary reason for not enrolling into hospice (Spencer et al., 2017).

Family Evaluation of Hospice Care

Timely Referrals and Length of Stay. Numerous articles chosen found short hospice stays is associated with higher rates of unmet needs, lower quality of life, increased cost of care, and increased deaths in hospital settings. Longer stays were associated with increased quality care, better pain and breathing management, and better following of end of life wishes (e.g. dying in preferred place) (Kumar et al., 2016).

A national Korean cross-sectional study using the Good Death inventory (GDI) and additional questions found 25.8% of bereaved family members thought hospice referrals were given too late (H.J. Jho et al., 2014). This group had higher rates of unaware terminal status, hospice stays less than 1 month, and significantly lower scores for physical and psychological comfort, staying in favored place, and living without concerning death/disease. It is also important to note pediatric patients were frequently in this group. Lack of communication plays a significant role in patient/family dissatisfaction.

A retrospective study by Mulville and Widick (2019) on 418 oncologic patients who passed in 2015 found the median length of stay to be 10 days. Moreover, 71% of participants stayed under 30 days, with 56% under 10 days. Short stays were associated with higher costs, especially at the end of life with most patients dying on aggressive, futile treatments in the hospital (Mulville and Widick, 2019).

Yamagishi et al. (2014) conducted a multi-center questionnaire to bereaved families who received hospice care throughout Japan. Of the 693 responses, 42% reported the timing as late or too late. These families had patients with a length of stay of less than 4 weeks and had a significantly lower perceived quality of care and lower quality of death and dying. The short stays were also associated with increased risk of major depressive disorder in family

caregivers, less satisfaction with hospice care of family caregivers, and inadequate symptom management.

Setting of Care. A retrospective cohort study performed by Unroe et al. (2019) found hospice satisfaction rates varied depending on where the care occurred. Home had the highest ranking (67% excellent), compared to assisted living (64%) and skilled nursing facilities (55%). As care becomes more institutionalized, less patient wishes are followed and families tend to get less information. However, less family teaching may be related to staff being more hands-on in patient care compared to patients living at home. Regardless, home is the setting of choice in most cases.

Cultural and Racial Disparities. Hospice clients are more likely to be non-Hispanic white (81%), speak English at home (94%), receive care in an integrated system (36%), and have a family-reported preference for pain relief over life extension (76%) (Kumar et al., 2016). These findings are not supportive of United States' demographics and are an indicator of racial disparities in health care. A cross-sectional study done by Holland, Luna, and Keene (2014) reported racial minority patients as more likely to express discontentment with hospice care; along with patients with more symptoms and those referred too early or too late. This result agrees with findings from Unroe et al.'s study (2019), where family members of black and latino descent reported more concerns regarding quality of care in areas of care coordination, honoring patient's wishes, and emotional/spiritual forms of support.

Strengths and Limitations of Literature

The literature review provided substantial information about barriers leading to the underutilization of hospice referrals and the effects of a late referral on patient/family outcomes. While the literature reviewed was up to date and consistent, some studies had a fairly small sample size. This may make generalizations of findings less accurate. Most studies regarding family satisfaction were conducted through surveys. The limitations of surveys are the timing in which they are given, the way they are formatted, and the response rate. Some studies had a poor response rate or were given much later after their loved one had passed away, which could lead to response bias.

Summary

The review of literature strongly suggested late referrals and short hospice enrollments are associated with unmet needs, inadequate pain and symptom management, and poor patient-physician connects. Patients receiving less than 1 month of hospice care reported the highest rates negative outcomes and dissatisfaction by their family members.

There have been multiple barriers to appropriate referrals: lack of standardization criteria for hospice admissions (poor sensitivity and specificity), patients'/families'/physicians' unwillingness to discuss end of life care, demographic barriers and disparities, and Medicare eligibility. These barriers do not stand alone, but they appear intersectionality.

Research Proposal

The purpose of this paper was to investigate the relationship between the timing of a hospice referral and the perceived quality of care by the family. Further research is needed on the barriers that influence the timing of a hospice referral, as well as barriers influencing the integration of a hospice program once a referral is made. The research questions proposed are

(1) How do experienced nurses describe barriers to the timing of a hospice referral; (2) Once a hospice referral is made, how do experienced nurses describe the barriers the family face in implementing hospice care?

A qualitative approach using in-depth interviews is proposed for this small, pilot study. The researcher will develop a 10 item open-ended questionnaire with additional demographic questions as the data collection method. A sample of 30 experienced oncology nurses will be selected as participants in the study through simple random sampling. Experience is defined as a minimum of 8 years working as a staff registered nurse. The questionnaire will include questions such as (1) In the last year, how many times have you perceived a hospice referral being made too late? (2) Describe the rationales surrounding what postponed the untimely hospice referral; and (3) Once a hospice referral has been made, list reasons you have seen families state for declining hospice service.

Upon approval from Dominican University of California's Institutional Review Board, the researcher will coordinate with the university's nursing director chair to send out the questionnaire to the nursing program's staff and faculty members. The researcher will also collaborate with Dr. Linnard-Palmer to send out the questionnaire to oncology nurses. The responses will be evaluated to identify themes and trends.

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