



## Patient Related Barriers Associated with Under Enrollment in Hospice: A Review

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### ABSTRACT

**Background:** Hospice care provides better quality of life compared with usual care, and focuses on caring, rather than curing. Many factors facing cancer patients at the last days of life prevent them from enrollment in hospice.

**Purpose:** to identify the barriers associated with hospice under enrollment for terminally ill cancer patients.

**Methodology:** an integrative literature review design was utilized, CINAHL, and PubMed were accessed by using key words (hospice, barriers, and cancer patients), and after applying inclusion criteria 8 articles were considered to meet the purpose of this review.

**Findings:** through reviewing literatures, 15% of hospice patients dis enrolled from hospice due to long-stay hospitalization, hospital death, & higher medicare expenditure with insufficient insurance coverage (financial burden), and some other factors may contribute in under enrollment in hospice such as knowledge deficiency with misconception of hospice terminology and scope, mistrust of health care professionals, death timing, and some policies may create a barrier and restrict access to care for hospice.

**Conclusion:** factors that may be associated with under enrollment of terminally ill cancer patients in hospice were lack of knowledge and misperception of hospice scope, emotional, physical and financial burden toward patient and family, death timing and bad quality of care.

**Keywords:** hospice, barriers, and cancer patients

### I. INTRODUCTION

Hospice is a concept of care designed to provide comfort and support patients and their families at the end of life, who no longer responds to treatments (Drisdom, 2012), especially when there is nothing left to be done. The word "hospice" comes from the Latin word "hospitium" means guesthouse referred to a place of shelter for rest. Hospice care provides better quality of life compared with usual care, as well as controlling of distressing symptoms. Identification and treatment of problems in the physical, psychosocial and spiritual domain are important in the last phase of life. It's well documented that the majority of the population, regardless of race or ethnicity, is unfamiliar with hospice (Washington, 2009). Nowadays we have to draw a direction for health care providers to address potential barriers to break the chain in order to increase the access to hospice care.

The purpose of this literature review is to identify the barriers associated with under enrollment in hospice services for terminally ill cancer patients through reviewing available literatures. In order to meet the purpose of this review, CINAHL, and Medline are accessed by using these key words (hospice, barriers, and cancer patients). This review is guided by Grounded Theory, the strategy of this theory is to study the interrelationship between meaning in the perception of the subjects and their action, and the sociologists were interested to study awareness of dying and social interaction.

## **II. METHODS**

A review of published literatures was conducted through EBSCO host Research databases of CINAHL, and Medline from 2009 - 2015. The key words that accessed to electronic data bases are: (hospice, barriers, and cancer patients). Articles were searched via CINAHL and Medline are 12 articles with inclusion criteria that matches: 1): research based study, 2): target populations were cancer patients, 3): adult populations were considered, 4): written in English language, and 5): limited time between 2009- 2015. Of total 12 articles that picked up from literatures were chosen to be of possible relevance to the review. Eight articles met the inclusion criteria were published from 2009 to 2015, they were considered as the core of this review. The earliest study was published in 2009, most of them were published in American Journal of Hospice and Palliative Medicine, studies that included in this review focused on barriers associated with underutilization of hospice at the end of life. They were conducted in USA, African American, china, and North California.

### **2.1 Methodological characteristics**

Eight researches which included in this review were qualitative studies, and descriptive, which used many models such as questionnaires and interview in order to collect information about the barriers of hospice under enrollment.

### **2.2 Sample characteristics**

Sample sizes in all chosen articles were varied from 20 to 591 participants, with age above 19 to 85 years; all included articles discussed the barriers that had been confronted by cancer patients which might impede their involvement in hospice services.

## **II. FINDINGS**

Despite many benefits of hospice, the general public continues resistance for enrollment in hospice, for several reasons or barriers; these barriers are:

### **2.1 Lack of knowledge**

Confusion about terminology and misperception of hospice care intent and scope still existed as a barrier for hospice under enrollment. Once patient and family are not ready for hospice and misconceive what hospice could add to existing care, they would be able to care of patient at home. (vig, Starks, Taylor, Hopley, and Edwards, 2010).

Yancu and her colleagues emphasize that physicians refuse to explain medical condition for the patient, and wait the family to start conversation about patient's case due to presence of different treatment approaches within the health care system; therefore lack of discussion and recommendation might be a barrier for attending hospice services.

### **2.2 Burden**

Hospice patients were receiving high cost medical care such as palliative chemotherapy, surgeries, radiations, blood transfusions, total parenteral nutrition, and frequent intensive home visits which were required for patients who live alone without caregivers at home, therefore patients need an insurance coverage to reimburse these costs, and some policies did not consider a complex needs for terminally ill cancer patients, these policies qualify the patient to use Medicare hospice if two physicians certified that patient is terminal, and has a life expectancy of six months or less (Melissa, Carlson, Barry, Cherlin, McCorkle, Bradley, 2012). Patient perception that hospice care is economically motivated might restrict the access to care and limit enrollment in hospices, a cumulative impact of financial resources such as lack of insurance and incomplete coverage were central issues. (Goepf, Meykler, Nancy, Mooney, Lyon, Raso, Julliard, 2008), and will negatively affect on patient emotionally and physiologically.

### **2.3 Death timing and peaceful death**

Hospice means acknowledging dying (vig, et al, 2010), physician's certification of terminal illness with bad prognosis lets patient and family to deny terminal diagnosis and refuse to accept that their patient will die (Yancu, et al, 2010), patients express discomfort while discussing terminality with other patients, nevertheless they desire to continue curative care, and waiting to hear about any other treatment options from their doctors (vig, et al, 2010), another may have inverse preference to hasten death and desire for mercy killing after terminal diagnosis. (Enguidanos, Yonashiro, and Cote, 2013).

### **2.4 Quality of care**

Mistrust of health care professionals can create a barrier to hospice referrals, in which quality of care influenced on patient's perception for best care location (Jenkins, et al, 2011). Carlson and her colleagues in their study displayed that more than 15% of hospice patients were unenrolled in hospice related to hospitalization, hospital death, and higher Medicare expenditure, it might be a marker to poor quality of care at the end of life.

## **2.4 Cultural, and religious factors**

Personal and cultural values may conflict with hospice philosophy; dissonance arose in cultural or religious perspective between patients and health care providers which might affect negatively on patient enrollment in hospice. (Goepf, et al, 2008). Jenkins and his colleagues clarify that most patients and families have religious beliefs and they are reluctant to have strangers in their homes. Use of hospice requires ultimate trust, when African Americans exposed to historical discrimination, they mistrusted of medical system and refused to have care from white health care workers in one's home, (Yancu, et al, 2010). In the study that was conducted in 2009 by Mellese and her colleagues hospice disenrollment was higher in non-white patients when compared with white non-Hispanic patients.

## **III. CONCLUSION**

This review provides significant insight into factors that may be associated with under enrollment of terminally ill cancer patients in hospice care such as lack of knowledge and misperception of hospice scope, emotional, physical and financial burden toward patient and family, death timing and peaceful death, mistrust of health care professionals and bad quality of care, all these cumulative events are considered as strong barriers for underuse of hospice care. We have to know that hospice knowledge which might be acquired from care givers not only increases the access to hospice enrollment, but also influences the hospice service utilization after enrollment.

## **IV. RECOMMENDATIONS**

Some policies would be adjusted to enroll these groups of patients in a nonprofit hospice organization to get a complete insurance coverage to meet a complex needs. Many hospice staffs must be trained and educated to increase the awareness toward conception and benefits of hospice services.

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