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End-Of-Life Care: Policy Recommendations for Ethnic Minority Groups

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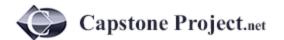Institution:

End-Of-Life Care for Ethnic Minority Groups

Introduction

In the past century, dying has exhibited high institutionalization. According to Gomes, Calanzani and Higginson (2011), the early 1900s periods were characterized by a significant number of deaths occurring at home. However, by the mid-20th century, industrialized nations were characterized by occurrences of deaths in health institutions. In spite of this development in the healthcare industry, most Americans preferred to die at their own respective homes, while only few percentage of the total population preferred end-of-life care. According to Tilden (2009), for how many decades, American deaths have always been controversial. This is because of the fact that of 2.5 million death cases, many were negotiated. Their deaths followed an extensive life-sustaining process of treatment and at the same time, decision making. This calls for American hospitals to put or cater palliative care units and specialists.

In a definition given by the National Institute of Health (NIH), end-of-life care is defined as "the care provided a person during the final stages of life" (Luce, 2010, p. 6). Although there is no exact definition or characteristic of a person's terminal or final stage, the "end-of-life" as a condition, pertains to "the presence of disease or disability that increases progressively and

requires symptom management" (Luce, 2010, p. 6). Thus, this stage is also referred as comfort care, hospice care, or palliative care.

The aspect of end-of-life care affects nurses, medical practitioners, and allied health professions. Through end-of-life care, healthcare provision practices in patients focus on final days or hours of their life. In addition, end-of-life care extends to care provision for individuals with terminal conditions or terminal illnesses that are incurable, progressive, and advanced (Clark, Armstrong, Allan, Graham, Carnon & Isles, 2014). Decision to withdraw life support or pursue aggressive treatment is determined by patients and their families. Some of the main players in the end-of-life care include social workers, nurses, doctors, and other professionals (Gomes, Calanzani, Curiale, McCrone & Higginson, 2013). Indeed, the goal of end-of-life care is to enhance comfort among patients (during their final days or hours). Some of the aspects of emphasis in the end-of-life care include life qualities for comforting the physical body of patients, natural death, symptom management, and pain control (Smith, White & Arnold, 2013). The process of providing end-of-life care involves service provision to distinct and unassimilated immigrants or racial groups. The past century has witnessed an increase in deaths within hospitals and nursing homes. However, national studies are yet to examine the implication of end-of-life care for ethnic minority groups. Knowing the differences between the condition of white and ethnic minority in ELC, including the factors that account to the existing disparities, is important in order to upgrade the quality of care and life that terminally ill patients receive (Loggers, et. al., 2009, p. 5559).
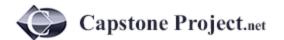
Ethnic Minority's Perception on End-of-life Care
(ELC)

Ethnic minority groups refer to racial groups or immigrants regarded as unassimilated or distinct. Perceptions of lacking assimilation and distinction among the racial groups or immigrants are associated with individuals who claim to represent or speak for the cultural majority (NHS Improving Quality, 2013). In the United States, Black or African Americans, Native Hawaiian, Hispanic or Latino and other Pacific Islander are some of the racial and ethnic minorities of greatest concern in health issues.

Sleeman, Ho, Verne, Gao and Higginson (2014) sought to examine the role of culture, ethnicity, and race in determining the nature of end-of-life care. Documentation indicated that the background of individuals provides a framework upon which aspects of individual patients could be addressed. In particular, the study established that race-related differences account for variations in individual preferences for intervention in the end-of-life. For instance, considerations of an individual's background were favored because of sensitivities surrounding possibilities of mistrust; yet trust and mistrust are helpful in establishing the end-of-life care. Coming from this assumption, one can imply that there is no single way to express the patient's preference on ending or extending his/her life.
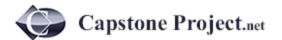
Another factor that affects the decision of ethnic minority to receive ELC heavily depended on religious, cultural, and ethnic values. The same claim was proven in the study conducted by Maddison, Fisher & Johnston (2011). They conducted a survey and affirmed that

different cultural and ethnic groups necessitate different approaches to the handling of impacts of illnesses. The study revealed that culture is a strong determinant of attitudes in decision-making for the end-of-life care. According to Luce (2010), ethnic groups in the United States believed that all possible means should be made in order to prolong life. This aligned to the study of Washam, where it uncovered that 84% of black Americans resort to religious coping. Hence, when specialists are not sure what the black patients really want, they usually decide to give aggressive care to the patient (Washam, 2010, p. 18).
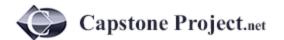
Racial Disparities on ELC

According to Grant (2010), Gender and Race are variables of diversity in healthcare profession that the institution fails to uphold. The research on health disparities is believed to be the key factor in order to improve the health status of all Americans, and to fully understand that it would be an effective way to defeat this intricate issue. The research on these disparities is based on racial and ethnical factors and has remained exceptionally consistent. Despite many medical milestones, members of certain race and ethnicity have constantly experienced a declining health status compared to other populations. As stated in the 2002 Institute of

Medicine, health disparities are "racial or ethnic difference in the quality of health care that are not due to access-related factors or clinical needs" (Campbell, Daigle & Smulski, 2007, p. 5).

It is also noteworthy to mention that the current health disparities that this group experience in the United States reflect the same experience of ethnic minorities outside the country. In fact, the study of Marie Curie (2013) on the end-of-life and palliative care for ethnic minority groups (Blacks and Asians) was focused in UK. Documentation suggested that growing evidence indicates that cultural and ethnic differences pose significant implications on the use of health care services, health care seeking behavior, illness experiences, and advanced disease. It was affirmed that whereas the strategy of end-of-life seeks to address differences or variations in the level and nature of care provision, inequalities are still existent. For instance, the study indicated that there is increasing international and national evidence regarding the low use of end-of-life care among ethnic minority groups, prompting the need to understand the relationship between aspects of culture and ethnicity, and the success of end-of-life care.

In the United States, there are also several studies conducted that showed racial disparities in the end-of-life care. For instance, Washam (2010) claimed that "white patients are three times as likely as blacks to get the end-of-life care of their choice" (p. 17), in spite of the fact that blacks have higher trust than white patients to their oncologists. Further, orders on DNR ("do not resuscitate") are more favorable to whites than black patients. As a matter of fact, the average age of African Americans who are usually dying after staying in end-of-life care is 55
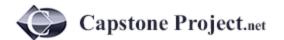
years old while whites are 60 (Washam, 2010, p. 17). It implies that blacks usually die earlier while whites continue to receive life-supporting treatment.

In a study conducted by Neuberger, Guthrie and Aaronvitch (2013), it was found out that in multicultural settings, the needs of ethnic minority groups are likely to receive little attention, attributed to the treatment as, in some instances, second citizens. Failure to emphasize on care needs of ethnic minority groups was also associated with the dominance of certain ethnic groups (at the expense of minority groups). Notably, the study indicated that clinicians who work out-of-hours care are unlikely to understand the needs and wishes of individuals from ethnic minority groups. As such, the study affirmed that advance end-of-life care is unlikely to be made. Failure to plan in advance for end-of-life care (for the benefit of ethnic minority groups) was also attributed to mistrust that leads to poor sharing of information.

Likewise, the study conducted by Philips & Taylor (2012) proved that despite the constant effort of health institutions and government to reinforce policies on equal access to palliative care and end-of-life care (ELC), blacks and people belonging to ethnic minority groups do not enjoy this. The study conducted by Loggers, et. al. (2009) revealed that most ELC specialist gave higher attention to white patients; hence, these patients were reticent to express their preference.

Problems that Ethnic Minorities Face in ELC

Philips & Taylor (2012) enumerated five reasons that contribute to ethnic minority's poor access to ELC. These reasons include the following: lack of patient referrals from the minority groups; lack of awareness and knowledge of ELC among the minority; lack of communication between ELC providers and patients; problem of trust that exists between minority and service providers; and lack of attainable information about prognoses and nature of diseases/illnesses (Philips & Taylor, 2012, p. 26). Aside from these factors, ethnic minorities encounter different barriers that often lead to poor end-of-life care service.
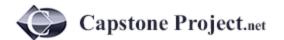
The study conducted by Washam revealed that palliative specialists lack good communication with their patients. Apparently, effective communication starts with the recognition of doctors to the needs of their patients. It is also noteworthy to mention that the needs of black patients generally differ from whites (Washam, 2010, p. 17). Hence, the next question is what should be the needs of the patients? Perhaps, the statement made by Trice Loggers, MD, PhD, summarizes the whole idea of effective communication: "Patients have to be in a state of psychological readiness to discuss end-of-life care… those forced to discuss it when they're not ready are more likely to get aggressive care and less likely to go to hospice" (cited by Washam, 2010, p. 18). Due to the fact that the first step that patients undergo is grieving, doctors and specialists should not yet discuss the issue on end-of-life care. Lack of good communication between practitioners and patient is deemed as a contributing factor that often leads to bad ELC service received by ethnic minorities.

According to Dr. Prigenson, as cited by Washam (2010), one of the most common problems that blacks usually experience in the end-of-life care is the lack of communication between care providers and black patients who have tumors. Another barrier that scholars discovered in the process of mediating the black patients and specialist includes the lack of education of the blacks. The average education that black patients achieved is 11.2 years as opposed to 13.8 years by whites. This fact aligned to the statement made by Dr. Volandes, "health literacy, and not race, that shapes patients' end-of-live choices" (cited by Washam, 2010, p. 18). To prove this, the author cited a previous study that showed educated African Americans who received the same level of aggressive care with white patients. Patients, regardless of race or gender, who possess good health literacy, have better understanding on intensive care and CPR than less health educated patients.

Another problem that exists among ethnic minority groups is their different view on advance end-of-life planning. These people usually despise written directives concerning death, because of "not wanting to tempt fate, not wanting to offend family members, or believing that written documents might be used against them to limit care or reduce costs" (Tilden, et. al., 2009, p. 364). Apparently, this only proves that the decision of ethnic groups is highly rooted to their cultural belief.

Another factor that affects the likelihood to receive the preferred end-of-life care is the patient's marital status. Washam (2010) indicated that "when they (patients) could not speak for themselves, their decision were in the hands of the person who knew them best" (p. 18). This is
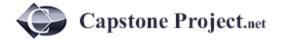
where the role of the patient's partner comes into picture. There were only 28% in the whole population of Black Americans in the country that are married. Hence, most of the time, the preferred end-of-life care are relied to the distant relatives, who know nothing or a little about the patient. In a nutshell, bad ELC service often experience by ethnic minorities is sometimes caused by lack of coordination with the patient's family members. As Tilden, et. al. (2009) claimed, families of the patients should always be ready to fulfill this responsibility.

Policy Recommendation

According to Georghiou, Davies, Davies & Bardsley (2012), effective end-of-life care is characterized by emotional support and desired physical comfort, promotion of shared decision making, treatment of dying patients with respect, provision of emotional support and data to family members, and coordination of care in respective contents. Based from the review of literature above, there are several policy recommendations that this study found out to be effective in order to eradicate or at the very least, alleviate the issue of racial disparity on ELC setting.
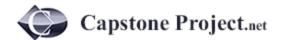
It was mentioned in the previous subchapter that communication between patients and practitioners is crucial in the ELC setting. In order to establish an open and balanced communication, the study indicated that negotiations of cultural differences are ideal. In multicultural settings, aspects of language barrier could arise. Therefore, it was deemed that the need for interpreters may be a great help to bridge the gap of communication.

There is also a need to further develop hospice, palliative, and ELC in the country. This pertains to the lack of programs, facilities, and specialists of this division. In reality, in spite of the growth of ELC in the country, less than 50% of the total number of hospitals in the United States does not offer this (Tilden, et. al., 2009, p. 364). Thus, it is not astonishing to see some practitioners condemning the expensive yet futile ELC service in the country. To make matter worse, palliative care division in the country had no financing program (Tilden, et. al., 2009, p. 365).

More importantly, this study emphasizes the importance of hearing the voice of ethnic minority in the process of developing health policies. This was aligned to the claim made by Goodridge (2010) – cooperation and trust should exist between hospitals and all stakeholders. Relevant authorities and governments should involve ethnic minority groups in the development of new policies, with improvements in ethnic monitoring targeted on a nationwide scale. Furthermore, it is imperative to enhance training skills and communication and, exhibit cultural competency among healthcare professionals.

Another significant element is the need to be sensitive and develop two-way conversations that are open. Such discussions should involve patients and their families. Instead of holding assumptions about patient behavior, healthcare professionals should establish strategies to reach ethnic minority groups; involving the encouragement and recruitment of personnel from ethnic minority groups. The role of healthcare professionals should also entail assessment of the effectiveness of interventions that seek to improve end-of-life care for ethnic

minority groups, besides evaluating current end-of-life care for ethnic minority groups. The sue of standardized tools or measures, and, adoption of different research methods that not only analyze data records but also the nature of patients over time is likely to yield positive outcomes in the end-of-life care for ethnic minority groups. Lastly, there is a need to improve the process of reporting or recording ethnicity to ensure that underrepresented minority groups receive adequate services in the end-of-life care.

Conclusion

In studying the health disparities that ethnic minorities experience in the United States, it is inevitable to consider cultural and ethnic values. This study only proves that heath depends on one's perception of "being healthy" and most of us take the notion that being healthy means to avoid activities that are risky to our body and well-being. However, the definition of health also lies on how people perceive culture as well. There were certain cultural practices that have influenced the way people determine their health status. For instance, we have seen that ethnic minority people usually prefer aggressive treatment while on the brink of life and death. Hence, in recommending a policy, it is important to understand ethnic minority culture. Practitioners and other stakeholders are expected to exercise patience, tolerance, and acceptance; prompting the aspect of listening to them carefully to gain knowledge about their beliefs and values.

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