

Review Article

Location of Death and End-of-Life Care

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Purpose: This study reviewed what the location of death (LOD) means as an outcome and how to use LOD to assess end-of-life (EOL) care. This study also examined the reason why LOD is significant for the quality of EOL care. **Methods:** A literature review was performed, using LODs and home deaths as outcomes in the field of EOL care, and analyzed the findings associated with key fields in regards to LOD. **Results:** Palliative care research used LOD, in particular, hospital death (versus home death) as a significant outcome when examining cost savings, quality of life care, and patient and family preferences. Based on substantial evidence from previous research, home hospice or continuous palliative care in non-hospital settings (i.e. homes, nursing homes) have been designed and available for dying patients in developed countries. **Conclusion:** The LOD delivers practical significance as an outcome for diverse reasons. In-depth examination on LOD in South Korea is needed despite limitations to interpretation of its meaning in the country.

Key Words: Hospices, Terminal care, Palliative care, Outcome assessment

INTRODUCTION

Interest in end-of-life (EOL) care has been growing due to continuously increasing medical expenditures compared to other expenditures for older populations in developed countries. Health policy makers are increasingly paying attention to expensive and intensive EOL care for dying patients because of the magnitude and trajectory of increasing demands in the decades to come. Additionally, lengthy dying processes for patients suffering from chronic, complex illnesses such as cancer and dementia require aggressive treatment and management and a greater demand for quality care in health systems. As a result, palliative care or hospice services have been designed and positioned as a distinct field in the medial arena since the 1990s in some developed countries (1-3).

Studies indicate that people prefer to die at home sur-

rounded by their loved ones; however, most people still end their lives in hospitals (4,5). Therefore, location of death (LOD) is a robust outcome in examining how to systemize EOL. LOD also serves an indicator of the effect of EOL care on dying patients and their families. With a well-developed EOL care system that offers better care for the dying, a "good death" is re-defined with an approach to measure "quality of life" at the end of life. In this context, LOD, i.e. home death, is embedded in the direct or indirect meaning of a "good death" in many instances.

This study aims to review the uses of LOD for different purposes as an outcome and to use LOD or home death (also referred to as an "out-of-hospital death") to assess EOL care. In addition, this study will examine previous studies into the significance of LOD for quality of care at the end of life and how LOD can be associated with the quality of EOL care.

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METHODS

Through reviewing previous research on LODs in different countries with advanced EOL care systems, this study investigated the significance of LOD and EOL care and the methods associated with using LOD as an outcome. Furthermore, this study assessed the current Korean EOL system related to LOD by comparing examples and evidences from other countries.

LOCATION OF DEATH IN END OF LIFE

1. Location of Death and Public Health

LOD has been regarded as an important outcome within palliative care that is supported by a growing body of research (6,7). Even though home death proportions are lower, it is still considered the preferred outcome (6,8), from the perspective of patients and palliative caregivers and from a cost standpoint (9,10). Several interpretations are made regarding LOD as an outcome. Hospitals are regarded to be less favorable because they are generally associated with more aggressive care and therefore higher costs (11-13). Hospital deaths imply that dying patients were significantly more likely to receive aggressive treatments until their last days, and such an approach leads to higher medical expenditures compared to those groups who received EOL care (2,14,15).

A few studies analyzed the change of place of care such as hospitals, nursing homes, palliative care and home or other settings for the last 3 months of life (6,16). The final place of care and LOD are significantly associated (17,18), and the quality of life of dying patients is associated with the place of care and final place of death (18). As interest in LOD has grown, transitions for the final 3 to 6 months of life has begun to be a subject of discussion for EOL care. Transitions among places of care prior to death, i.e. hospitals or skilled nursing homes, have been examined and were significantly associated with medical expenditures and quality of care (19-21).

With the prevalence of chronic life-limiting diseases on the rise and the dying phase being increasingly protracted (22), societies are increasingly confronted with dying and care needs during the dying trajectory. From a public health perspective,

it is important to understand EOL care at a population level and the significance associated with LOD.

2. Location of Death and Palliative and Hospice Care

There is a growing consensus that the aggressiveness of EOL care has an important influence on the quality of care at the end of life (22,23) as well as the costs (2,24,25) of care for the last phase of life. A number of studies indicated that shorter stays in hospice or late referrals to hospice for dying patients were significantly associated with poor quality of life care (26,27).

Additionally, advanced directives proved useful for planning EOL care matters and determining out-of-hospital deaths, thus limiting aggressive efforts to lengthen the lives of dying patients (11,28). Planning for EOL care in advance led to cost savings and a reduction in hospitalizations at the population level in the U.S. (11). Using administrative data from Medicare claims in the U.S., a number of studies have demonstrated that hospice programs reduced hospitalizations, costs, and even lowered hospital deaths (25,29). Hospitalization is costly, particularly for patients at the end of life. Because of technical and medical developments and a concurrent belief in the possibilities of treatment, treatments persist that focus on cures and life-prolonging interventions until the very last stages of life, even when they are no longer warranted or beneficial in hospital settings (14,30). This type of care is described as aggressive treatment at the end of life (22,30). In a Dutch study, a small proportion of transitions in the last 3 months of life involved the use of palliative care settings or hospice (16). Dying patient involvement with palliative care and hospice care was a significant factor associated with readmission to hospitals prior to death, hospital (inpatient) death, and cost savings (25).

Tangeman and his colleagues found that the recipients of hospice appeared to have lower hospitalization costs among adults in western New York. Furthermore, care coordinated with post discharge hospice services appeared to substantially reduce the likelihood of readmission (31). It was evident that in-home palliative care significantly reduced the costs of medical care at the end of life and increased satisfaction of care (32). It is apparent that hospice is a significant predictor for preventing hospitalization at the end of life and for promoting non-hospital deaths which lead to cost savings and quality of

life care.

The involvement of multidisciplinary palliative home care teams and home care team support has led to more people dying out-of-hospital in Europe and the U.S. (17,33).

In addition, care transitions such as hospitalizations were more frequent among patients residing at home without any home care (61~73%) than among patients residing in a care home (33~40%) or palliative care unit among patients who died non-suddenly (16,34). The evidence demonstrates that EOL care use, or the availability of palliative care increased home death rates in developed countries where supports for dying at home were provided for those with this preferred wish.

On the other hand, South Korea is a particularly interesting case as it has one of the highest hospital death percentages within an international place of death study (35-37). A majority of deaths occur in hospitals in South Korea (38) but little is known about the association of hospice use, types of care, and its influences on LOD. Previous research into this topic is limited to U.S. Medicare beneficiaries and a few European studies. Although it may be tempting to conclude that EOL care in South Korea is more medicalized, more aggressive, and more costly, further investigation is needed. It is necessary to understand what decisions and interventions are preceding hospital deaths, and whether it is indeed indicative of aggressive and expensive care, or whether a large proportion is comfort care. Due to the short history of including EOL care in National Health Insurance system, a majority of EOL care is currently being provided in hospitals (39), and there are also low rates of utilization of EOL care (6,8). At this time, it may be difficult to examine the effect of hospice or palliative care on LOD in South Korea. However, there is still a need for future in-depth research to examine LOD, as an outcome in South Korea associated with EOL care use and quality of care at the end of life.

3. Locations of Death and Factors Associated with LOD

The body of research on EOL care illustrates that hospice use has increased over time after the official program was initiated in the United States (40,41) and as Medicare benefits expanded to include hospice enrollees as non-cancer patients. Accordingly, the proportion of non-cancer hospice patients has increased. In particular, patients with dementia constitute a

growing proportion of hospice enrollees in the U.S. (42). Patients with non-solid tumors may be less likely to die at home because they have multiple options for prognosis and treatment. Such options are key to quality EOL care and home death (43). With increased access, the number of hospice and palliative care patients will continue to grow. As a consequence, EOL care use and hospital deaths would be expected to increase at the same time. Therefore, knowing the factors associated with LOD among dying patients may give some indication how to design better EOL care systems.

A systematic review study that analyzed 58 studies of over 1.5 million patients from 13 countries revealed the effect of 17 factors on LOD, of which six were strongly associated with home death. The six factors were: patients' low functional status (odds ratios range from 2.29 to 11.1), their preferences (2.19~8.38), home care (1.37~5.1) and its intensity (1.06~8.65), living with relatives (1.78~7.85), and extended family support (2.28~5.47) (43). Factors related to illness, the individual, and the environment (healthcare input and social support) were found to be the most important. Therefore, home health or home hospice is an important factor associated with increasing home deaths in countries which have developed delivery systems for EOL care through diverse venues.

Most research efforts have focused on disclosing factors associated with home deaths or hospital deaths in the context of supporting home death eventually (7,13,43-45). A patient who is expected to die after a short period of time and prefers to die at home has a higher probability of dying at home in Europe and the U.S. compared to other countries because of existing home care options.

HOME DEATH, HOME HOSPICE AND THE CONTINUOUS CARE MODEL

This study examined the varied aspects of LOD related to EOL care through primarily reviewing different studies conducted in Europe and North America. The significance of LOD goes beyond the physical place of death to include the larger context of EOL care in many cases.

The availability of a home hospice or palliative care service unit in hospital and strong wishes for a preferred place for death have been associated with home deaths (46). More importantly, the availability of home care for dying patients

appears to be a significant factor in increasing the number of home deaths (13,33) in most studies. Thus, delivery systems for palliative care services have been extended outside of medical settings for dying patients facing an expected death. As a result, different services and payment systems were developed according to the care settings and the components of service packages in other countries.

The number of home hospice agencies and available reimbursements (i.e. per diem or fee for service) for hospice and palliative care outside of hospitals seem to make a difference in developed countries (3). Bekelam and his colleagues reported that the United States (cohort of decedents aged > 65 years) and the Netherlands had the lowest proportion of decedents die in acute care hospitals (22.2% and 29.4%, respectively) compared to five other European countries: Belgium (51.2%), Canada (52.1%), England (41.7%), Germany (38.3%), and Norway (44.7%). Service reimbursements for EOL care and available EOL care outside of hospitals were associated with outside of hospital deaths. Consequently, a health care system can influence the LOD through delivery of EOL care.

It was encouraging to see a home hospice pilot project launched recently in South Korea after years of effort (6,8). Home hospice is able to fill the unmet needs of patients for EOL care at home in case EOL care needs to be provided outside of hospitals.

Comprehensive models for palliative and hospice care in hospitals and in communities for dying patients has been addressed in previous studies (25,47-49), including care at home and in promoting home deaths. Different care goals in different care settings eventually help to meet different demands for care intensity (25). Hospice use in different settings such as a nursing home versus a home has been compared (50) numerous times. Hospice care in institutionalized settings is more common in the U.S.

It is essential to develop delivery systems that differentiate patients by care level and needs and provide EOL care in hospitals and at home, depending on their needs.

There are not comparable formats of EOL care in different settings in South Korea at the moment; however, the service format is evolving to provide more care outside of hospitals (39). Patient profiles as EOL care beneficiaries should be discussed and expanded to include dementia and other terminal

illness rather than only cancer patients. Along with the extension of EOL care in the National Health Insurance program, the quality of care should also be guaranteed. LOD can serve as an indicator for many purposes when carrying out well-designed studies into EOL care.

CONCLUSION

Most people are born in and die in medicalized hospital settings in developed countries, but there has been a visible effort to alter the LOD for pragmatic reasons. Home death has been considered an ideal outcome and has been promoted in developed countries with built-up EOL care settings in their health delivery systems. Despite limitations in fully implementing concepts of LOD, LOD in South Korea needs to be examined further and in-depth studies conducted to understand diverse perspectives in EOL care for practical purposes.

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