



Barriers to Early Palliative Care

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This article aims to discuss the barriers hindering cancer patients from receiving early palliative care, which has been demonstrated to be more effective in improving quality of life and controlling symptoms. Specifically, there are barriers in four aspects of delivering early palliative care. First, the difficulty of starting discussions about early palliative care and the lack of adequate appointment time can impede communication between oncologists and patients and their family members. Second, determining the timing of referral and deciding upon and applying a standard for referral can be barriers in the process of referral from oncology to palliative care. Third, palliative care patients and their family members can face difficulties regarding in what format and by whom the services will be delivered. Fourth, biases, misinformation, and inaccurate beliefs can be barriers in the process of patients and their family members accepting care. In order to facilitate early palliative care, research and policy regarding these barriers are necessary, along with efforts made by medical staff.

Key Words: Palliative care, Early medical intervention, Health services accessibility, Communication, Neoplasms

Received November 27, 2020
Accepted November 30, 2020

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There is a tendency in South Korea to confuse the terms “hospice” and “palliative care”. Even in the Life-sustaining Treatment Decision Act, the term “hospice/palliative care” is used and shortened to “hospice” [1]. However, in the literature from the United States and Europe, hospice and palliative care are presented as similar, but distinct terms with some different characteristics. Generally, palliative care is a broader concept that refers to supportive care for patients with advanced disease and includes intervention programs that are provided in urgent care and community settings. Instead, hospice is a form of palliative care based in the community provided to patients who are close to the end of life and their family members [2]. According to the conventional understanding, palliative care aims to improve patients’ quality of life after the discontinuation of curative treatment by controlling symptoms, but recently, palliative care has started earlier, closer to the time of

diagnosis, and it accounts for a larger proportion of the care compared to curative treatment as the disease progresses [3]. It has been pointed out that in the current approach, there is no clear line between curative care and palliative care based on disease progression. The concept of palliative care is becoming more dynamic, and palliative care can increase or decrease based on symptom severity or the need for symptom control even when curative care is being administered [4].

This evolution in the concept of palliative care occurred because many studies proved that early palliative care is effective in improving quality of life and controlling symptoms, and some studies even demonstrated prolonged survival [2]. Thus, it is now being emphasized that earlier palliative care interventions are required. Patients with advanced cancer have various physical, psychological, and social problems and care needs, so they cannot be taken care of by a single person. A multi-

disciplinary team approach is a core characteristic of palliative care [5], and this is also the case for early palliative care. This article discusses potential barriers to early palliative care for cancer patients.

The process of palliative care during the treatment and progression of cancer entails an oncologist sharing the patient's status with the patient and his or her family, discussing the treatment plan, referring the patient to the palliative care team, and the palliative care team providing services to the patient and his or her family members. Therefore, barriers can be encountered at four stages of the process: communication between oncologists and the patient and family, the referral from oncology to palliative care, the provision of palliative care to the patient and family, and acceptance of palliative care by the patient and family.

1. Barriers in communication can occur between oncologists and patients and their family members

According to a qualitative study conducted in Belgium, oncologists experienced difficulties in starting conversations about palliative care due to their level of emotional connectedness with patients, personal emotional difficulties, and a lack of experience and skill [6]. It has been reported that this difficulty increases depending on the response from patients and family members. For early palliative care, the discussion about palliative care needs to happen at an earlier time point, which can exacerbate these difficulties. In the South Korean medical environment, this problem is further complicated by the lack of sufficient time to explain the situation to patients and family members. A study based in South Korea found that difficulties in finding adequate time for appointments, fears of giving patients and family members the impression that they have given up, and not wanting to destroy the hopes of patients and their family members were reported as barriers to palliative care referral [7]. In order to promote early palliative care, efforts to improve communication between oncologists and patients and their family members, sufficient appointment time, and financial compensation for these appointments should be implemented.

2. Barriers occur in the process of referral from oncology to palliative care

How oncologists determine the timing of referrals from oncology to palliative care is an important question, especially regarding early palliative care since its effectiveness depends on care beginning at the proper time. This issue also relates to the communication barrier discussed above. Oncologists may believe that treatment should continue due to their personal philosophy or may avoid uncomfortable conversations related to death [8]. In real-world settings, some patients are referred to palliative care and others are not, depending on the discretion of the oncologist rather than objective evaluations of the patients' clinical status. In the clinical trials that demonstrated the effectiveness of early palliative care, however, every patient received palliative care regardless of his or her clinical status [5]. Since both scenarios could present issues with the inappropriate allocation of palliative care (that is, some patients who need palliative care might not receive it, or vice versa), an automated system should be developed that selects and refers patients who have high palliative care needs to palliative care based on objective standards [2,5].

Standards based on palliative care needs (e.g., severe physical symptoms, requests to hasten death, and delirium) and standards based on timing (e.g., within 3 months of the diagnosis of progressive cancer with a life expectancy shorter than a year) have been suggested [2,5]. In order to determine palliative care needs, a selection process must be conducted, and implementing standards based on timing is problematic because it is difficult to predict the length of survival. Therefore, it is also suggested that referrals to early palliative care should be triggered by hospitalization in the past 30 days or for more than 7 days among patients with progressive cancer [9]. Regardless of the specific method, the standards or situations for applying early palliative care should be evaluated. Since communication with patients and their family members must occur, regardless of whether a selection tool is used or timing-based standards are applied, limitations in terms of appointment times and personnel could result in barriers in referring patients to early palliative care at the right moment. Therefore, early palliative care can be facilitated by providing support in terms of adequate staffing and remuneration.

3. Barriers are encountered in the provision of palliative care to patients and their family members

Practical considerations need to be addressed regarding the method and form of palliative care services. Currently, the most ideal modality for early palliative care is outpatient care, either associated with a cancer clinic or independently from a cancer clinic [10]. The outpatient format is appropriate for linkage between community-based hospice, palliative care wards in hospitals, and consultation-based palliative care teams. In this format, patients with relatively good function can attend outpatient appointments regularly; these patients have some time left, and do not require hospitalization despite having symptoms that necessitate palliative care [10]. According to the treatment records from the MD Anderson Cancer Center in the United States, four doctors, 12 nurses, and 3 counselors/psychiatrists treated around 6.8 new patients and 26.7 existing patients per day [10]. In comparison to real-world circumstances in South Korea, the situation described above involves a surplus of medical staff caring for a relatively small number of patients. In this setting, the fact that a palliative care team needs to provide services in a separate outpatient format can be a barrier. A reimbursement system for early palliative care should be established as outpatient palliative care or supportive treatment for cancer patients, rather than consultation-based hospice care, which might be avoided due to the requirement for patients to have end-stage cancer or the use of the term “hospice”. For such a program, support in terms of personnel and space, as well as education for existing hospice and palliative care staff, will be required.

4. Barriers can occur in terms of acceptance by the patient and his or her family members

Even with the efforts made by oncologists and palliative care teams, care cannot be provided unless patients and their family members want early palliative care. According to a large-scale study on knowledge and beliefs about palliative care in the United States, a majority of respondents (53.0~81.3%) knew that palliative care and hospice are different, understood that receiving palliative care does not mean that anti-cancer treatments have been discontinued, and recognized that palliative care does not mean giving up, but 42.5% thought that pal-

liative care was related to death [11]. In a study conducted in Australia, 44.7% of cancer patients thought that palliative care was only related to end-of-life care, and 39.8% responded that they would be scared if they are referred to palliative care [12]. Cancer patients responded that they would feel more comfortable about palliative care if they could receive palliative treatment and anti-cancer treatment at the same time, and they preferred the term “supportive care” over “palliative care” [12]. Thus, knowledge and beliefs about palliative care held by patients and their family members can be a barrier. In the United States and Australia, where palliative care is more advanced than in South Korea, a sizable proportion of people have misconceptions about palliative care. Therefore, in order to facilitate early palliative care in South Korea, it is necessary to listen to patients’ and their family members’ perspectives and to carefully explain the advantages of early palliative care.

To conclude, four types of barriers to early palliative care were discussed. In order for more terminal patients, including cancer patients, to receive palliative care services, which have been proven to have clear benefits, at an earlier time and to benefit from the resulting improvements in quality of life, further research should be conducted on these barriers, appropriate policies should be developed, and effort from medical staff is required.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

SUPPLEMENTARY MATERIALS

Supplementary materials can be found via <https://doi.org/10.14475/kjhpc.2020.23.4.252>.

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