

Current situation and dilemma of hospice and palliative care in the aging context

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Abstract. With the deepening of the aging of society, the management of serious diseases is becoming more and more important. Therefore, the need for hospice and palliative care is growing rapidly these years. As a kind of well-rounded way of caring, hospice and palliative care can not only relieve patients' pain physically, but also support them psychologically and make them fit in society. Effective care can enhance the quality level of patients' daily lives to ensure their dignity and respect their wishes at the last stage of their lives. Many countries are taking measures to develop hospice and palliative care to improve people's life quality. Different strategies have been used to reduce patients' pain and improve their life quality. However, dilemmas still exist at the level of patients, providers, and policy. This article comprehensively analyzes the current situation and dilemma of hospice and palliative care in the aging context and provides potential solutions.

Keywords: hospice care, palliative care, aging society

1. Introduction

According to the Center to Advance Palliative Care and the American Cancer Society. Hospice is a system of care delivery for patients at the end of life. Hospice and palliative care is a way to release patients and families from the pain of diseases or aging problems. The aim of it is to improve patients' and families' life quality. Although hospice and palliative care are two different nursing types, they can often be used interchangeably [1]. Within the context of the increasing aging population, the perspective of hospice and palliative care becomes unavoidably important.

The Chinese government is developing hospice and palliative care and has made great progress in it. For example, the Chinese government has published a range of policies. This guidance covered various aspects of hospice and palliative care services from public awareness to service content [2]. Similarly, hospice care is developing consistently in Canada. Patients in Canada have been provided with new choices, such as access to medical assistance in dying (MAiD) [3]. However, hospice and palliative care in every country are still not perfect nowadays. There are some material or cultural problems. For example, the patient's family is afraid of witnessing the death. From the aspect of hospital management, bed occupation, and economic effects are unavoidable problems.

This article presents the existing application, current dilemma, and potential solutions in hospice and palliative care under the challenges of an aging population.

2. Current application

Hospice and palliative care have developed rapidly nowadays. Different strategies have been used for patients suffering from different diseases to improve their life quality. With the help of these strategies, patients can be cared well and their life quality can be improved.

2.1. Music therapy

Music therapy can reduce nurse visits and reduce medicine consumption. The declined consumption of medicine can not only ensure better health of the patients but also helps save costs. Apart from that, many patients showed a declined degree of emotional disturbance and an improvement in life quality, and the patients are usually satisfied with music therapy. As a complementary therapy, music therapy can effectively improve patients' life quality and reduce costs to some degree [4].

Music therapy is equally practical in improving the relationship between patients and their families. Music therapy offers opportunities for communication. Patients and their families usually memorize the patients' favourite songs, choose songs to express their feelings, and create lyrics by filling in the blanks offered by the therapists in music therapy. This enables patients and their families to explore their true thoughts and their motivations. For example, a patient chose a song named "I Only Care About You." for his mother to show how much he cares about her. This indirectly represented the feeling that the son really wanted to take better care of his mother. Music therapy offers the opportunity for expression. For instance, patients can indirectly express their farewell by creating lyrics for their families. Music therapy offers a chance for patients to interact with their families peacefully. By reading the lyrics made from patients' families and friends, every participant can know each other better, which creates better atmosphere. This helps patients and their families to calm down and improve their relationships [5].

2.2. Inpatient care

Many types of research have proved that Inpatient palliative care is effective, such as reducing the severity of the symptoms and improving the Inpatient care has two main compositions: professional teams which are in charge of symptom control, and acute palliative care units which provide instant symptom-control treatments for those who need instant medical help, especially for those patients with only a few days left. Before patients receive hospice and palliative care, the Palliative Care and Rapid Emergency Screening tool (P-CaRES) will be used to assess whether the patient is suitable for hospice and palliative care. This assessment ensures early referral, which can be an important part in the inpatient specialist palliative care [6]. Inpatient hospices and palliative care units are important in caring terminal cancer patients, especially those who are unable to stay at home. Interdisciplinary nursing provides support for inpatient hospices and palliative care units [6].

In inpatient care, patients usually receive care from a comprehensive aspect. Music therapists, pharmacists, specialized palliative care nurses, and others cooperate with each other and provide professional help to patients, which can improve their life quality and relieve their pain. For example, a patient with a stroke may encounter different symptoms, such as code status changes and dysphagia. Under these conditions, cooperation is needed between the decision-makers and the incapacitated stroke patients to make every decision to meet the patient's wishes [6].

2.3. Community-centered palliative care

In community-centered palliative care, nursing teams usually come to the patients' homes to assess the situation. The nursing teams usually provide professional advice after their assessment. For patients with declining physical status, community-based palliative care is more practical.

Under the situation of an aging population, many old adults suffer from complications before their death. This makes them require more physical and mental support in the care. Community-based palliative care can share the burden of the overloaded comprehensive hospitals to meet senior citizens' needs timely. According to the research, patients accepted more nurse visits, shorter waiting time, and fewer emergency room visits during community-centered palliative care. Although community-centered

palliative care has fewer volunteer and professional staff and fewer training hours, community-based palliative care can provide equally qualified palliative care as inpatient care [7].

3. The challenges

Although hospice and palliative care have been applied to various aspects and have many interventional forms, hospice and palliative care nowadays have encountered some barriers. For example, the lack of related knowledge, misunderstandings, access to hospice and palliative care, and communication barriers. Respectively, there are dilemmas from the level of patient, provider, and policy.

3.1. Patient level

Lacking relevant knowledge and misunderstanding of the services have become the reasons for communication barriers, especially for old people. According to the research, less than 28.8% of the American adult population has heard about the concept of palliative care. The misunderstandings such as connecting palliative care with death automatically and considering palliative care as giving up still exist. The widespread lack of knowledge can affect the patients in deciding whether to accept palliative care or not [8]. According to research in the Czech Republic, 42% of the old adults in the research are unwilling to die in the hospice because of the lack of relevant knowledge and misunderstandings. Old adults usually neglect the importance of hospice and palliative care, making them more likely to have negative thoughts. Lower-educated older adults show the fear of death greater than those with high-level education [9].

The cultural effect is another unavoidable barrier. As one of the aging societies in the world, China is heavily influenced by the concept of filial piety. This makes many individuals in China resist hospice care. The patients' families tend to try their best to ensure the patients receive positive treatment to extend their lifespan at the final stage of patients' lives, but this can bring much pain to the patients. Apart from that, talking about death may be considered as a taboo. Therefore, individuals are likely to refuse to talk about any death-related topics, including hospice and palliative care [10].

3.2. Provider level

A common barrier at the provider level is a lack of professionals. According to Hammoda Abu-Odah, the shortage of nursing staff, especially the lack of professional female nurses and few auxiliary personnel is a great problem in hospitals [10]. The lack of social workers with professional palliative care knowledge makes supporting the patients based in the community difficult. According to research on community care, one social worker was in charge of up to 500 patients. This research also revealed that some hospice and palliative care teams had no professional nursing staff in psychology [11]. Therefore, patients usually needed to wait for a long time to keep in touch with their careers, and to make matters worse, their careers were often unable to provide them with enough support, because those careers were lack of related knowledge. As a result, the patients cannot get enough spiritual support as the palliative care caseload is too heavy for the staff.

Apart from that, medical hierarchy across specialties may affect patient's access to hospice and palliative care. Some doctors reported that it was difficult to decide when to refer patients to hospice care because patients' course of disease varies from each other [1]. Therefore, many patients are unable to have access to hospice.

The negative thoughts and misunderstandings about hospice and palliative care caused by the lack of knowledge are another key barrier at the provider level. Palliative care is usually concerned with a kind of failure after treatments. It is widely believed that palliative care is used only when you have nothing to do with your disease. These negative ideas lead to the situation that providers resist to use of palliative care.

3.3. Political level

The scale of hospice care institutions is not big enough and the geographical distribution is uneven. According to the research in China, most institutions are located in advanced metropolises like Beijing,

Tianjin, Shanghai, and Guangdong. The shortage of funds has been considered the key barrier to providing hospice and palliative care. Because of this, many professional hospice care hospital are facing with the problem of lacking bed space and advanced medical facilities, which makes it tough for doctors and nurses to take measures to make patients live better. Laking support from the government and a complicated political situation has negative effects on the provision [1].

Hospice and palliative care are not a priority from the policy aspect. The extent of policy concerning hospice and palliative care is still insufficient. Usually, relevant services are additional items processed in the contest of a general policy. The details on how to take into practice are rare, such as how to let patients accept these services and how to avoid potential ethical problems.

4. Solutions

Potential solutions for the dilemma of hospice and palliative care need help from patients, providers, and the policy. Extensive education is needed to change the current situation of lacking knowledge and to eliminate misunderstandings. The referral patterns should be improved to realize the early intervention of hospice and palliative care. And more policies should be published to ensure a positive development atmosphere of hospice and palliative care.

4.1. Public education

Public education is a vital part of reducing public misunderstandings and ignorance. The public should have more access to the targeted didactic palliative care resources. Media can provide more solutions to the public, similar to the “chain of survival” for first aid. Diverse ways of propagating should be advocated for public education. All the educational resources can be shared in diverse forms, including online materials, video clips, or leaflets, to meet comprehensive needs. After learning the related knowledge, patients and their families can understand the importance of applying comprehensive hospice and palliative care early [12].

4.2. Provider improvement

Referral patterns should be improved to make early intervention in hospice and palliative care common. The situation that clinicians only hand over work at the end of life should be changed. Therefore, a mode that can adapt to early palliative care is crucial. A screening mechanism should be established to identify patients who need the care most, thus providing them with hospice and palliative care. Then, the team should meet the patients’ needs as soon as possible to solve their problems at the early stage. For example, complications and mental problems in the treatment of cancer. [12] By improving the shift from active treatment to hospice and palliative care, patients’ stigma of receiving relevant care services can be reduced.

Professional education on hospice and palliative care is another essential part, which is vital in solving the recent problem of lacking sophisticated providers. Hospice and palliative care lectures and clinical practice should become a vital part of medical school and nursing school courses. Apart from that, the idea of palliative care should be implemented in the whole process of medication. Hospice and palliative care should not be a task that is only managed by palliative care teams. All clinicians should be equipped with sufficient hospice and palliative care knowledge. For those who have been in clinical practice, the chance to have continuing education should be given to ensure their high-quality palliative treatment skills [12].

4.3. Political support

To exaggerate the importance of early intervention, developing and enacting a strategy targeted at propaganda and education is necessary. By encouraging mainstream media, websites, and newspapers to spread new policies and new tendencies of hospice and palliative care, the social atmosphere on relevant services will become better [10]. With the monitoring and proposal of the government, the education of hospice and palliative care can be enhanced at the public health level [12].

Medical teams need enough funds to provide various specialized services for different patients. Therefore, the government should provide more financial support for organizations and wards. For example, include hospice and palliative care into the scope of medical insurance reimbursement [10].

Apart from that, the medical resources should be optimized. The distribution of medical resources should become more equal with the promotion of related policy. Measures such as diverting patients to primary healthcare institutions through referral policies are vital for relieving pressure on some comprehensive hospitals. This enables a balanced development of care services. Therefore, uneven geographical distribution and care services can be relieved [10].

5. Conclusion

"Good death" is people's pursuit of life quality and dignity. Hospice care is to provide physical, psychological, spiritual and other aspects of care and humanistic care for terminally ill patients before their death, control pain and discomfort symptoms, improve life quality, help patients die comfortably, peacefully and with dignity, and provide support for their families in all aspects.

Concerning the current situation of hospice and palliative care and the aging society, the importance of hospice and palliative should be exaggerated. Although it has been used in various ways, including music therapy, inpatient care, and community-centered palliative care and many countries have developed different ways to exaggerate it, challenges in the level of patients, providers, and policy still exist. There is still a lack of measures that can be universal. In terms of these challenges, public and professional education, a change in referral patterns, and policy support should be applied to tackle these barriers. Digital health is an area of knowledge and practice related to the development and use of digital technologies to improve health. Digital health is to meet the requirements of high-quality health development, with digital or knowledge as the key element resources. In the future, hospice care can be combined with digital health, improving continuity of care and patient satisfaction.

References

- [1] Nelson, Katie E et al. "Sociodemographic Disparities in Access to Hospice and Palliative Care: An Integrative Review." *The American journal of hospice & palliative care* vol. 38,11 (2021): 1378-1390. doi:10.1177/1049909120985419
- [2] Lu, Yuhua et al. "Advancements in hospice and palliative care in China: A five-year review." *Asia-Pacific journal of oncology nursing* vol. 11,3 100385. 26 Jan. 2024, doi:10.1016/j.apjon.2024.100385
- [3] Antonacci, Rebecca et al. "Gaps in Hospice and Palliative Care Research: A Scoping Review of the North American Literature." *Journal of aging research* vol. 2020 3921245. 5 Nov. 2020, doi:10.1155/2020/3921245
- [4] Potvin, Noah et al. "Music Therapy and Nursing Cotreatment in Integrative Hospice and Palliative Care." *Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association* vol. 23,4 (2021): 309-315. doi:10.1097/NJH.0000000000000747
- [5] Hsieh, Fu-Nien et al. "Music Therapy to Facilitate Relationship Completion at the End of Life: A Mixed-Methods Study." *Journal of music therapy*, thae005. 14 Mar. 2024, doi:10.1093/jmt/thae005
- [6] Castro, Jacqueline Alcalde et al. "Integrating Palliative Care into Oncology Care Worldwide: The Right Care in the Right Place at the Right Time." *Current treatment options in oncology* vol. 24,4 (2023): 353-372. doi:10.1007/s11864-023-01060-9
- [7] Lin, Cheng-Pei et al. "A Comparison of the Survival, Place of Death, and Medical Utilization of Terminal Patients Receiving Hospital-Based and Community-Based Palliative Home Care: A Retrospective and Propensity Score Matching Cohort Study." *International journal of environmental research and public health* vol. 18,14 7272. 7 Jul. 2021, doi:10.3390/ijerph18147272

- [8] Flieger, Signe Peterson et al. "Lack of Awareness and Common Misconceptions About Palliative Care Among Adults: Insights from a National Survey." *Journal of general internal medicine* vol. 35,7 (2020): 2059-2064. doi:10.1007/s11606-020-05730-4
- [9] Bužgova, R., and M. Zapletalova. "Assessment of Older Adults' Attitudes to Death, Palliative Treatment, and Hospice Care in the Czech Republic." *Aging Medicine and Healthcare* 12.2 (2021): 53-61.
- [10] Ling, Meng et al. "A Review of the Current State of Hospice Care in China." *Current oncology reports* vol. 22,10 99. 28 Jul. 2020, doi:10.1007/s11912-020-00959-y
- [11] Rattner, Maxxine, and Cheryl-Anne Cait. "Nonphysical Suffering: An Under-Resourced and Key Role for Hospice and Palliative Care Social Workers." *Journal of social work in end-of-life & palliative care* vol. 20,1 (2024): 8-25. doi:10.1080/15524256.2023.2272590
- [12] Alcalde, Jacqueline, and Camilla Zimmermann. "Stigma about palliative care: origins and solutions." *Ecancermedalscience* vol. 16 1377. 28 Apr. 2022, doi:10.3332/ecancer.2022.1377