Special Report 2

Palliative Care Quality Challenges in Taiwan

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The Economist Intelligence Unit (EIU) evaluated the quality of death in different countries in 2015, and Taiwan ranked sixth in the world and first in Asia among 80 countries. While we were all thrilled with the achievement, Control Yuan sent a letter to the Ministry of Health and Welfare, pointing out that there are still many deficiencies in Taiwan's end of life care, and that more efforts are needed to improve it, and that improvement must be tracked annually. In light of these almost opposite results, is the quality of palliative care in Taiwan adequate or not?

Palliative care is holistic care for the critical or terminally patients that covers physical, psychological, social, and spiritual aspects, as well as the needs of the patients and caregivers, and is provided in a variety of settings such as the patients' home, institution, or hospital. In 2018, the International Association for Hospice and Palliative Care (IAHPC) proposed a consensus definition of hospice and palliative care: Palliative Care is an active holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers[1].

The report published by the Worldwide Hospice Palliative Care Alliance[2] discusses in detail the changes in palliative care from the traditional to the 21st century. The traditional model targets terminal cancer patients with prognosis of months to weeks. The 21 Century holistic hospice palliative care expands its target to all patients with severe, progressive, life-threatening diseases. Traditionally, only patients with progressive deterioration have been accepted, but in the future, palliative care will be provided for progressive, but often sudden, deterioration. The traditional model is to choose either curative or palliative care, but the current concept is that both can be administered simultaneously as needed, with the primary purpose of managing complex or severe clinical conditions. The provision of service is no longer limited to institutions only, but is gradually developing into community-based holistic care to provide a systematic service. Due to the rapid increase in aged population, the development of community-centered supportive environments and palliative care based on public health are recent trends in various countries.

The implementation of palliative care can not only improve the quality of life of patients and caregivers, but also reduce the cost of medical care according to research, especially the introduction of home palliative care, which can effectively reduce the use of emergency room and intensive care unit[3]. Many countries have made palliative care a part of the official health care system, and regular monitoring of palliative care becomes mandatory to ensure it satisfy a certain quality standard.

In the United States, the fourth edition of Clinical Practice Guidelines for Quality Palliative Care was published in 2018[4], and many studies have been conducted to support the importance of these eight components in improving the quality of palliative care[5]. The United Kingdom published its End of Life Care for Adults: Service Delivery in 2019[6], and Australia published its National Palliative Care Standards in

2018[7]. In addition, the White Paper on Hospice and Palliative Care Policy in Taiwan, written by the Taiwan National Health Research Institute[8], sets out three visions: (a) respecting individual uniqueness and values and providing all people with the opportunity for quality of life and death, (b) providing integrated, Five-Whole care that optimizes comfort and quality of life, and (c) ensuring the expertise, attitudes, and skills of the care team and providing coordinated care. Each country has framed the basic components of the quality of palliative care in a holistic and macro perspective.The assessment of the quality of palliative care must be based on relevant indicators and reliable information sources. Generally speaking, information sources can be divided into three categories: population-based administrative data, clinical data, and patient-reported outcomes. General administrative data is more readily available and provides a complete outlook of the overall health care system; clinical information provides a comparison between care results and benchmarking care; and patient-reported outcomes directly reflect the impact of care. [9]

Quality of Palliative Care at the Macro Level

The Economist Intelligence Unit (EIU) evaluated the quality of death in 40 countries in 2010[10] and ranked Taiwan 14th in the world and 1st in Asia in terms of the quality of terminal care. The evaluation was based on four main components: financial burden of terminal care, external environment, quality of care, and accessibility of services. Taiwan performed well in the first three categories, but lacked in accessibility (ranked 19 out of 40 countries/regions), so the training of community hospice and Class B hospice care workers can partially solve the accessibility issue. In 2015, the think tank conducted the second survey on the quality of death for terminal patients[11], and among the 80 countries assessed, Taiwan ranked 6th worldwide and 1st in Asia, followed closely behind the top five: UK, Australia, New Zealand, Ireland and Belgium. Palliative

Table 1 Comparison of major strategies for palliative care in the US, UK and Australia

U.S. Clinical Practice Guidelines for Quality Palliative Care[4]	1.Structure and process of care 2.Physical aspects of care 3.Psychological and psychiatric aspects of care 4.Social aspects of care 5.Spiritual, religious and existential aspects of care 6.Cultural aspects of care 7.Care of the patients nearing the end of life 8.Ethical and legal aspects of care
End of life care for adults: service delivery [6]	1.Identifying terminally ill adult patients and their caregivers 2.Assessing the need for holistic care 3.Supporting Caregivers 4.Providing appropriate information, including shared decision-making 5.Reviewing the current treatment and stop unnecessary treatment 6.Creating an advance care plan 7.Regularly revisit requirements 8.Sharing information across services 9.Providing comprehensive professional care 10.Coordinating respite care to ensure seamless integration of patients into different services 11.Providing holiday, weekend and out-of-hour service
National Palliative Care Standards 5th [7]	1.Initial and ongoing assessment incorporates the person’s physical, psychological, cultural, social and spiritual experiences and needs 2.The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan 3.The person’s family and carers’ needs are assessed and directly inform provision of appropriate support and guidance about their role 4.The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan 5.Care is integrated across the person’s experience to ensure seamless transitions within and between services 6.Families and carers have access to bereavement support services and are provided with information about loss and grief 7.The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care 8.Services are engaged in quality improvement and research to improve service provision and development 9.Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles

and healthcare environment, Human resources, Affordability of care, Quality of care, community engagement. The result of the survey, which consisted of five main categories, were further investigated. In palliative and healthcare environment, Taiwan was ranked 5th from 15th in 2010; in human resources, ranked 10th; in affordability of care, ranked 7th from 10th; in quality of care, ranked 6th from 10th; and in community engagement, ranked 5th from 19th.

Common characteristics of countries with high quality of death include effective national hospice and palliative policies, high levels of public expenditure on health care services, extensive hospice training resources for general and professional healthcare workers, adequate funding for hospice and palliative care, availability of opioid pain medications, and high levels of public awareness of hospice care. Although Taiwan is ahead of Singapore and Japan in overall ranking, it is ranked 25th and 24th out of 80 countries in terms of “shared decision-making” and “availability of specialised palliative care workers”, which need to be addressed.

In addition to the EIU ratings, Clark (2019) compares the development of palliative care in 198 countries and categorizes countries around the world into six levels of palliative care based on 10 indicators, including provision of services, geographical spread of services, range of available funding sources for palliative care, existence of national strategy or plan for palliative care, existence of legal provision to support palliative care, availability of morphine and other strong opioids, country consumption of morphine per capita, training programs for professionals in palliative care, education for pre-qualification doctors/nurses, and existence of meetings, associations, journals, conferences. The first category indicates that there is no known palliative care activity, and category 4b indicates that palliative care services at an advanced stage of integration to mainstream health care services. There are 30 countries (15%) that fall into category 4b, and Taiwan, along with the United

Pre-meeting workshop of PCOC (Palliative Care Outcomes Collaborative Model) on November 19, 2019, from left: Wang Shu-Chen, Deputy Director of the Department of Nursing, Hualien Tzu Chi Hospital; Australian doctoral student from Bhutan; Director-General Wang Ying-Wei; Professor Kathy Eagar, chair of PCOC; Dr. Barbara Davison, Director of PCOC; and Huang Chiao-Wen, Secition Chief of the National Health Service, discussing the Taiwan and international PCOC Collaborative Project.

Kingdom, Canada, Australia, Japan and South Korea, falls into this category. [12]

Quality of Palliative Care in Terms of Clinical Care and Patient Perception

High-quality care encompasses safety, clinical effectiveness, and a positive patient experience, which is defined as a sense of self-control, respect, and patient-centered care[13]. International palliative care assessment tools take into account both clinical effectiveness and patient experience, such as the UK's Integrated Palliative Care Outcomes Scale (IPOS)[14] and the Australian Palliative Care Outcomes Collaboration (PCOC)[15], both of which include professional assessment scales and patient self-representation scales and patient changes can therefore be clinically captured. The IPOS is assessed every three and seven days during patient admission, while the PCOC is assessed daily during patient admission, and in the case of home palliative care, the assessment is done during home visits. The patient assessment, after digitally recorded, can be used for comparison of changes in patients as well as quality monitoring against benchmark data.

Conclusion

When discussing the quality of palliative care from the macro perspective of the health care system, Taiwan has done exceptionally well in different assessment indicators around the world. On the other hand, palliative care quality can also be assessed from clinical care and patient perceptions, which has not been comprehensively promoted in Taiwan and has led to a lot of doubts about the actual quality of palliative care. Learning from the experience of the UK or Australia and introducing internationally validated assessment tools is a feasible way to improve the quality of palliative care in Taiwan in the future.

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