



Hospice
Foundation of
Taiwan

HFT Newsletter

Forever Love, Endless Care

July 2024



Hospice Foundation of Taiwan Wins the 7th Y.L. Lin Civic Achievement Award

33 Years of Promoting Equal Rights to a
Good Death in Taiwan

Hospice Foundation of Taiwan's 2022 Hospice & Palliative Care Advocacy, Education, and Research Project

- Precision Identification of Death Timelines through Data:
Opening a Quality End-of-Life Dialogue
- Kaohsiung Medical University Builds Community-Based Home
Hospice Care Network Fulfilling the Wish to Die at Home:
Completing the Journey of Life



Hospice Foundation of Taiwan
www.hospice.org.tw

No. 45, Minsheng Road, Danshui District, New Taipei City 25160 Taiwan
Tel: +886-2-28081130 Fax: +886-2-28081137 Email: hospice@hospice.org.tw

Like us on Facebook



Like us on Instagram



Hospice Foundation of Taiwan Wins the 7th Y.L. Lin Civic Achievement Award

33 Years of Promoting Equal Rights to a Good Death in Taiwan

In 1990, the Hospice Foundation of Taiwan ("the Foundation") was established through the joint efforts of MacKay Memorial Hospital and Shuang Lien Presbyterian Church, marking the official start of hospice care development in Taiwan. Over the past 34 years, the Foundation has progressively improved the medical environment for hospice care in Taiwan, cultivated relevant professionals, and actively promoted hospice care to the public. Additionally, the Foundation has been instrumental in initiating and advocating for related legislation, serving as the strongest support for patients and hospice care teams. This has ensured that patients and their families receive appropriate care and maintain a comfortable and dignified quality of life when facing terminal illness.

Joining Hands with Students to Promote the Concept of Hospice Care

The dedication of the Hospice Foundation of Taiwan was recognized by the Y.L. Lin Hung Tai Education Foundation in October 2023, awarding them the 7th Y.L. Lin Social Welfare Achievement Award. Dr. Yuh-Cheng Yang, Chairman of the



Hospice Foundation of Taiwan, remarked that the award added warm firewood to the furnace that has been burning for 34 years. "It not only helps us continue to burn but also reminds us of the social responsibilities we bear."



Following the award, the Y.L. Lin Hung Tai Education Foundation further invited the Hospice Foundation of Taiwan to serve as a topic partner for the 21st ATCC National College Business Case Competition. They sought creative proposals from college students, hoping that through innovative thinking, they could collectively advocate for hospice care. The three-month competition saw multiple proposal and implementation stages, with the team *Kingdom of Jinji* from National Taiwan University securing first place in the semi-finals and eventually winning the national championship, beating three other teams representing businesses and public sectors.

The *Kingdom of Jinji* team consisted of five National Taiwan University students: Min-Xuan Shen, Min-Xiang Zhang, and Zhe-Kai Ni from the Department of Economics, Cai-Ying Chen from the Department of Finance, and Jun-Yuan Zheng from the



Department of International Business. Min-Xuan Shen, a sophomore, noted with a laugh that the journey had not been easy, as the team members initially had no understanding of palliative care and held the stereotypical view of hospice care as merely "waiting to die."

Through collaboration with foundation specialists and touching real-life stories, the team gradually broke down misconceptions and grasped the essence of hospice care. Min-Xuan Shen deeply felt that hospice is not a place of darkness, but a pursuit of light. "We gradually understood that entering hospice care means living in another dignified form. *Five-Aspects of Holistic Care* not only addresses the patient's physical, mental, and spiritual needs but also supports their families."



Moved by these stories, they centered their proposal on touching narratives, naming their project *Good Day, Hospice. How About a Story?* During the implementation phase, they promoted hospice care in coffee shops and set up stalls at cultural markets for charity sales and storytelling.

"We hope to become seeds of hospice care. As we deepen our understanding, we aim to pass on the correct concepts to those around us." Min-Xuan Shen believes that participating in the competition was just part of the journey. Once hospice care is rooted in one's heart, they become a part of the hospice support team, using their personal efforts to enhance public understanding of hospice care.

Preparing in Advance for Hospice Care Needs of a Super Aged Society

In addition to continuing to promote hospice care, the Hospice Foundation of Taiwan is adapting to changing times and social environments, bringing hospice care to where it is most needed. With the elderly population steadily increasing, Taiwan is expected to officially become a super-aged society by 2025. The Ministry of Health and Welfare estimates that the number of people in need of long-term care will exceed one million within the next three years. In response, the Foundation began planning a series of long-term care hospice promotion programs years ago, including organizing long-term care hospice courses and cultivating professional talent. Additionally, to increase the willingness of long-term care institutions to offer hospice services, the Foundation has linked hospice service networks with long-term care networks, and introduced hospice clinical education and related resources.

Since its establishment 34 years ago, the Hospice Foundation of Taiwan has



consistently undertaken significant responsibilities, but it has never walked alone. Throughout its journey, numerous partners have joined the cause, including the Y.L. Lin Hung Tai Education Foundation. The Foundation will continue to build a patient-centered hospice care network in Taiwan, extending hospice care from hospitals to homes and long-term care institutions. Regardless of where life's end occurs, everyone will have the right to equal hospice care and a dignified death.



Precision Identification of Death Timelines through Data: Opening a Quality End-of-Life Dialogue

At Taipei City Hospital Zhongxing Branch, a data-driven study was conducted to evaluate the accuracy of attending physicians' judgments regarding patients' end-of-life stages and the reasons behind these judgments. The hospital is actively promoting the concept of a good death to over 6,000 healthcare workers. This study, which spans different hospital branches and various diseases, is the first of its kind in Asia and has received support from the Hospice Foundation of Taiwan's 2022 Palliative Care Advocacy, Education, and Research Program.

Mr. Lu, who was in his 70s, was admitted to the hospital due to a brain hemorrhage and unexpectedly discovered that his cancer, which had been stable for seven years, had metastasized to his brain, lungs, and liver. Initially, chemotherapy and medication stabilized his condition, and his prognosis was quite optimistic. Unfortunately, during the pandemic, Mr. Lu contracted COVID-19, which drastically weakened his immune system, leading to the deterioration of his condition and his premature death.

Ms. Chen, aged 49, had been battling breast cancer for four years, having experienced multiple recurrences and metastasis to her lungs and liver. Although her tumor initially shrank, and her attending physician believed that she could live for 1 to 3 years with injections and oral medication, Ms. Chen refused to continue aggressive treatment and passed away a year later.

In Mr. Lu's case, external infection factors played a role, while in Ms. Chen's case,



it was the patient's refusal of aggressive treatment. Both of them passed away sooner than their attending physicians had anticipated, but fortunately, they had engaged in Advance Care Planning (ACP) during their treatment process, and made the difficult decisions about their end-of-life care ahead of time. Thus, after activating their Advance Directives (AD), they were able to die in the manner they wished.

Physicians Being Overly Optimistic Can Create Blind Spots in Hospice Initiation Strategies



"End-of-life discussions are crucial for patients to understand their prognosis and make care decisions that truly reflect their desires," said Dr. Tai-Yin Wu, Deputy Director of Taipei City Hospital Zhongxing Branch. Initiating these conversations early not only helps patients pass away peacefully but also provides their families with an opportunity to heal from trauma and find the strength to move forward.

In most clinical settings, the attending physician controls the *activation button* and decides whether to involve hospice care. However, this strategy has its blind spots because not every physician can clearly explain the direction of medical treatment and prognosis or accurately identify the timeline of death every time. This often prevents them from stepping back to a guiding role and introducing social workers, psychologists, nurses, and chaplains to facilitate end-of-life discussions.

"Physicians naturally hope their treatments will be effective, but this expectation can lead them to make overly optimistic judgments," said Dr. Wu. The progression of terminal illnesses and patterns of medical care differ, making accurate prognostication challenging. Additionally, a physician's professional training and experience can affect their accuracy. If physicians are overly optimistic and hospice



care is introduced too late, patients may not pass away peacefully, families may struggle to cope with grief, and numerous medical disputes could arise.

Dr. Kuang-Yu Hsu, Director of the Division of Hospice Palliative Care at Zhongxing Branch, added that predicting death timelines is difficult, and communicating about them is equally challenging. Patients' fear of death and society's high expectations for longevity can make healthcare staff apprehensive about the reactions that may follow from stating that "death is near." This may cause team members to resist crossing medical hierarchies and passively leave end-of-life communication to the attending physician.

Asia's First Large-Scale, Cross-Hospital, Cross-Disease End-of-Life Prediction Study

Dr. Tai-Yin Wu's research project-- *Physicians Are Over Optimistic in Recognizing Inpatients' Survival and Palliative Care Needs: A Large Scale Multi-center Study in Taiwan*--received funding from the Hospice Foundation of Taiwan's 2022 Palliative Care Advocacy, Education, and Research Program. This study aims to use data to evaluate the accuracy of physicians' judgments regarding end-of-life stages and identify the related causes.

The study traces back to 2015, when Dr. Sheng-Jean Huang, a prominent advocate for palliative care in Taiwan, was the Superintendent of Taipei City Hospital. He actively promoted the concept of a dignified death across seven hospital branches, reaching over 6,000 healthcare workers. Starting in March 2016, nurses at Taipei City Hospital's seven branches were required to use the *Taiwan Palliative Care Screening Tool* (TW-PCST) to assess all inpatients based on disease severity, comorbidities, functional status, and deterioration. If the score was 4 or higher, the attending physician had to answer three questions: (1) "Would you be surprised if this patient dies within the next 6 to 12 months?", (2) "Is the patient in the terminal



stage?", and (3) "Does the patient need palliative care?" Based on these responses, a decision would be made about involving palliative care. Dr. Tai-Yin Wu noted that Taipei City Hospital still actively requires all physicians to complete these assessments within three days.

Taipei City Hospital's Big Data Center meticulously recorded these assessments. In 2019, Dr. Tai-Yin Wu began collaborating with the hospital's Chief Data Officer to analyze data from patients who died during their hospitalization between 2016 and 2020. The analysis examined the relationship between physicians' responses to the three assessment questions and the patients' actual survival periods. This cross-hospital, cross-disease study is the first of its kind in Asia, as previous research generally focused on single diseases or specialties, aiming to improve the accuracy of end-of-life predictions.

Disease Types and Gender May Impact End-of-Life Prediction Accuracy

Dr. Tai-Yin Wu presented findings from the study indicating that only 88% of patients were accurately identified by their attending physicians as being in the last 6 to 12 months of life. The key factor influencing this accuracy was the physician's experience; those with more extensive experience tended to make more accurate predictions. Physicians with specialized training in palliative care, who had shadowed in hospice wards or conducted home palliative visits, were better at assessing patients' remaining lifespans.

The type of disease also influenced the accuracy of predictions. Malignant diseases like cancer had more predictable progression, allowing physicians to more accurately confirm that patients were entering the terminal stage and to connect them with palliative care resources early. Conversely, patients with non-malignant diseases had more variable survival times. For instance, cancer patients approached



the end of life twice as quickly as non-cancer patients in cases where physicians predicted death within a year. Organ failure patients might die 2 to 5 years later, while dementia patients could live for 8 to 9 more years, making it more challenging to determine the optimal time for palliative care intervention.

The study also highlighted that gender differences affected both the acceptance of palliative care and the assessment of end-of-life stages. Women were generally more receptive to palliative care, while men were more likely to continue ineffective treatments until the final two weeks of life. Dr. Wu noted that these differences might be linked to societal expectations based on gender roles. Men, often seen as the primary earners in their families, are expected to fight for survival, leading families to invest more in prolonging their lives. Although women typically carry a smaller economic burden, some chose to forgo aggressive treatment to avoid placing emotional and financial strain on their families.

Dr. Tai-Yin Wu emphasized that there are no right or wrong choices in these decisions. However, during family meetings, the palliative care team must carefully understand the underlying reasons for these choices and appropriately connect resources to ensure that patients' true wishes are honored.

The Importance of Deeply Rooted Palliative Education

Dr. Tai-Yin Wu emphasizes that relying solely on attending physicians to initiate palliative care is insufficient, calling for improved strategies. An effective immediate strategy is to have nurses directly initiate end-of-life conversations after assessing patients



with high TW-PCST scores, rather than passively waiting for physician judgments. Additionally, physicians need to be informed about the accuracy of their death



predictions. For example, Taipei City Hospital has been providing feedback to physicians on death cases since 2018, helping them understand discrepancies in end-of-life assessments and build more interpretive experience.

"The most crucial aspect is embedding palliative care education and training deeply within domestic medical education," Dr. Wu stated. Just as geriatric medicine has become a mandatory part of clinical medical education, physician training is gradually evolving. Encouraging physicians to pursue further training in palliative care, in addition to specializing in palliative care, will enhance the implementation of palliative care in clinical settings. This will provide patients with more or adequate time for end-of-life discussions and ensure a meaningful conclusion to their lives.



Kaohsiung Medical University Builds Community-Based Home Hospice Care Network-Fulfilling the Wish to Die at Home: Completing the Journey of Life

The current home hospice care model includes not only hospital-based teams but also community-based home hospice teams composed of primary healthcare personnel from local communities. These community teams offer care of comparable quality to hospital teams and provide the advantages of more immediate and accessible service, making the goal of dying at home more attainable.

As the concept of palliative care becomes more widespread, public acceptance has notably increased. Dying at home is a common wish among terminally ill patients and the general public. Traditionally, home hospice teams have been made up of hospital-based medical staff, but logistical constraints such as transportation and staffing issues can hinder timely care. When faced with rapidly changing conditions in terminal patients, family members often struggle to manage alone and may opt to transfer the patient to the hospital, resulting in the patient spending their final days in transit between the home and the hospital.

To enhance the capacity for home hospice services and fulfill the wish of dying at home, the Ministry of Health and Welfare introduced *Community-based Home Hospice Care (Type B) Benefits* in 2014. This policy relaxed training requirements for physicians and nurses at local health centers, clinics, and home nursing stations, encouraging these primary care providers to establish hospice teams and offer



community-based home hospice services.

Creating a Win-Win Scenario for Hospitals, Communities, and Patients

Dr. Chien-Yi Wu, who trained at Kaohsiung Medical University (KMU) Chung-Ho Memorial Hospital during his residency, has been deeply involved in hospice care. Following his interest in the field, he remained at the hospital as a family medicine physician, focusing on palliative care.



Through his work, Dr. Wu discovered that despite government efforts to promote community-based hospice care, 95% of home hospice care was still managed by hospitals. He identified that patients often preferred to stay with their original hospital teams due to established relationships, while community clinics were less engaged in hospice care due to lower insurance reimbursements and limited confidence in providing such care. This reluctance has made it challenging to build a robust community-based hospice network.

Dr. Wu has long aspired to develop a community-based hospice system similar to those abroad. "I hope to integrate hospital and community home hospice resources to provide more suitable care for patients."

To advance community hospice care, the Ministry of Health and Welfare introduced the *Promotion of Community Hospice Care Model Project*, selecting key hospitals to provide professional support to local clinics, health centers, and community nursing institutions. The goal was to connect hospital and community resources to deliver comprehensive home hospice services. In 2018, Dr. Wu successfully secured funding for KMU, making it the only hospital in Kaohsiung to be part of



this project.

After receiving the subsidy, Dr. Wu led the KMU hospice team to Nantou to learn from Dr. Yih-Chyang Weng, Director of Radiation Oncology at Nantou Hospital, who had been successfully promoting community-based hospice care in Nantou since 2008. Subsequently, they organized a meeting with various clinics and home nursing stations in Kaohsiung, forming the *KMU Community-based Home Hospice Network*.

Once the network was established, KMU's hospice case managers evaluated and communicated with patients and families to understand their preferences and locations, initiating referrals to appropriate community-based hospice teams. KMU served as the core hospital, providing guidance and establishing a collaborative care model with community teams. "We're not concerned about losing patients; we refer them when appropriate to help build community care capacity, aiming for a win-win situation for KMU, the community, and the patients," says Dr. Wu.

In the initial stages, KMU's team conducted the first visits with community teams to build confidence among patients and community providers. They also created a LINE group for continuous communication between the community teams and KMU, ensuring a seamless transfer mechanism. Regular monthly meetings were held, inviting community teams to the hospital for case discussions, thereby enhancing their care capabilities and practical experience.

Dr. Wu addresses concerns about patient deterioration after referral by explaining, "We reassure patients and families that referrals are intended to find nearby teams for suitable care. Community teams are professional providers, and if acute issues arise, KMU will manage them. Community-based home hospice care is a two-way process; we continue to monitor and assess referred patients to ensure high-quality care."



Connecting with Community Pharmacies to Establish a Comprehensive Network

Dr. Wu notes that even after the one-year project concluded, KMU's community-based home hospice network has continued to thrive, referring 70 to 100 patients annually to community home hospice teams. These teams have now become quite adept at providing hospice care independently, with KMU offering supplementary support as needed.

The integration and expansion of this network have broadened KMU's home hospice services beyond a 30-minute drive, extending north to Lujhu and Alian, and south to Daliao and Linyuan. This expansion ensures a wider coverage area and better supports patient needs.

To assess the effectiveness of community-based home hospice care, Dr. Wu conducted a retrospective study analyzing the medical records of 138 KMU home hospice patients from the project period. The study found that 48 patients were successfully referred to community home hospice care. "Once the hospital initiates the referral process, about 30% of patients are willing to accept community-based hospice care, demonstrating the critical role core hospitals play."

Regarding visit frequency, physicians from community clinics often visit patients only when their schedules allow, due to their other practice commitments. In contrast, community nurses show higher flexibility and frequently visit patients. Consequently, KMU refers patients to community nurses first, who then coordinate with physicians to form community-based home hospice teams. Dr. Wu explains that the regular visits by community nurses help them build



strong, trusting relationships with patients and their families. Many patients receiving community-based home hospice care are able to spend their final days at home, successfully fulfilling the goal of dying at home.

Furthermore, the community-based home hospice network also involves community pharmacies. Patients in palliative care often require narcotic pain relief medications, which are expensive and classified as controlled substances, making it less likely for general pharmacies to stock them. This leads to patients having to return to the hospital for their medications, despite opting for community-based home hospice care. To address this issue, the Kaohsiung City Health Bureau has promoted the *Controlled Drug Collection Cooperation Model for Home Hospice Care*, encouraging community pharmacies to collaborate with community home hospice care clinics to handle prescriptions for controlled substances. This initiative allows patients' families to conveniently pick up medications nearby, enhancing the overall community-based home hospice care network.

Prospective Study to Develop Home Hospice Shared Decision Making (SDM)

Dr. Wu has long wished to analyze the effectiveness of KMU's community-based home hospice promotion using medical economics. In 2022, he applied for the Hospice Foundation's *Hospice Care Advocacy, Education, and Research Project* grant to conduct a prospective study on *Cost-Effectiveness Analysis of Community-based Home Hospice Care*.

Unlike previous retrospective studies that analyze data after the fact, this prospective study obtained consent from patients and their families in advance and passed ethical review. It involved designing questionnaires and recording the actual time spent at each stage of patient care to conduct a cost-effectiveness analysis of community-based home hospice care.



Dr. Wu admits that due to limited manpower, accurately calculating the time spent during visits was challenging, and some data were recorded afterward. "However, we strive to collect data as soon as possible after the patient's death, rather than waiting a year to review medical records as in previous retrospective studies."

For this research, Dr. Wu and the KMU team developed a *Shared Decision Making* ("SDM") assessment form for home hospice care, addressing the issue of unilateral decision-making previously predominant in hospitals. Dr. Wu integrated his experiences and knowledge from developing the community-based home hospice network into the SDM assessment form to help patients participate in decisions and select the most appropriate care model.

Dr. Wu's research indicates that in 87 SDM cases, the average anxiety scores of patients and families (on a scale of 10) decreased from 3.5 before SDM to 2.5 after SDM, significantly reducing their anxiety and worry.

Dr. Wu explains that facing the unknown inevitably causes anxiety. The SDM assessment form not only educates patients about home hospice care, but also assists them in making informed choices between hospital and community-based home hospice teams based on SDM guidance. This approach provides patients with more options and helps ensure that their final moments are free of regrets.

