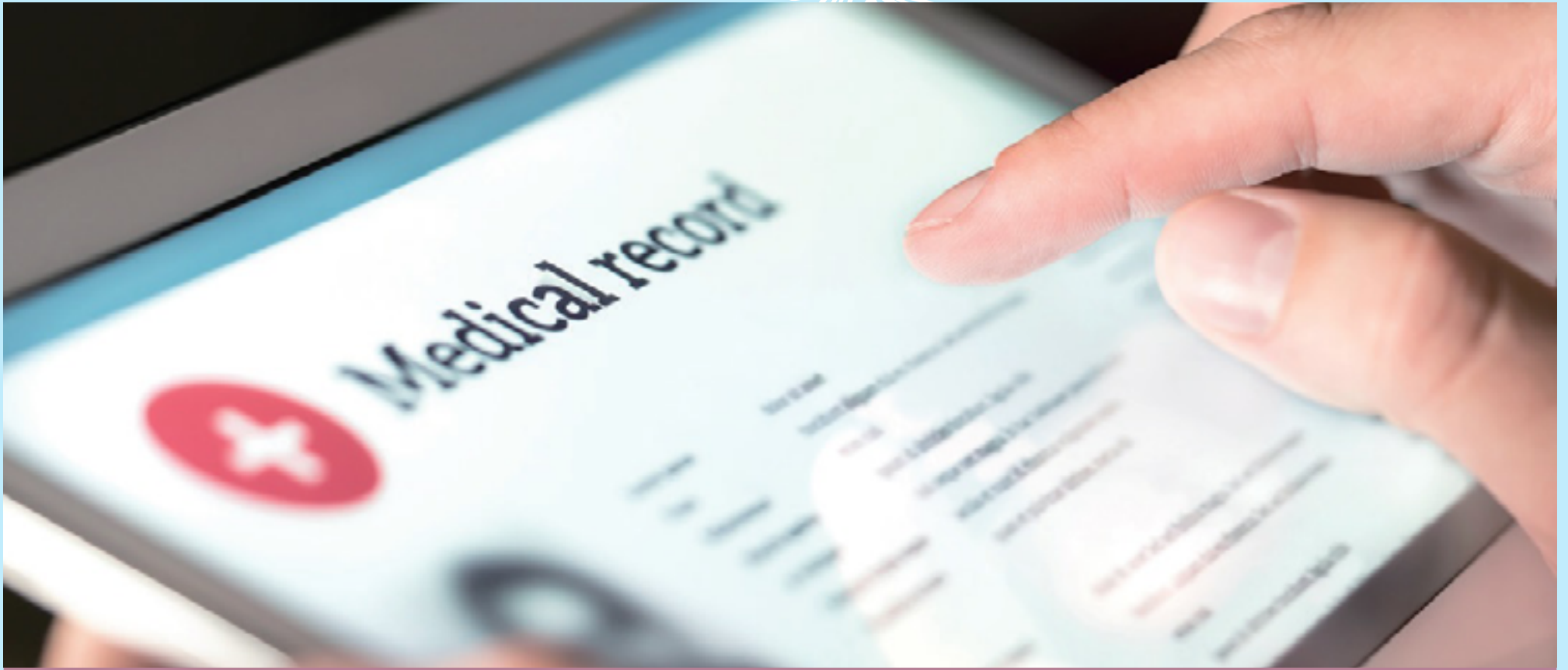


Hospice
Foundation of
Taiwan

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Forever Love, Endless Care

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Let's Sit Down and Talk Lectures on Life in the Neighborhood

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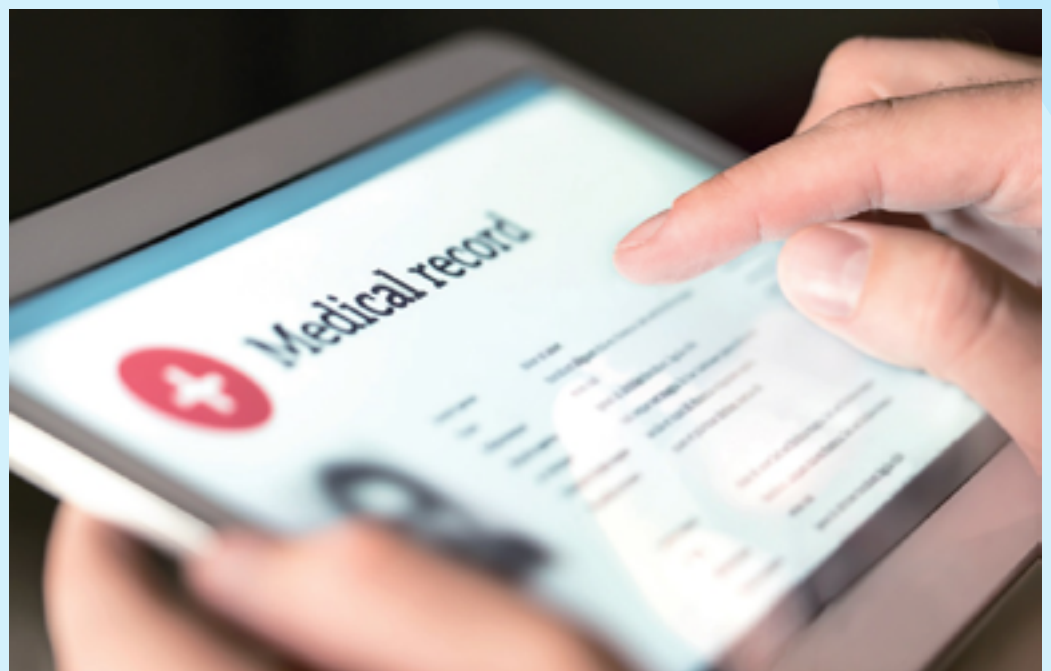


Covid-19 Pandemic Blocks Visits and Medical Care

The Covid-19 pandemic has been raging through the world for over a year, and as such, hospice and palliative care in numerous countries has also been greatly affected. Nevertheless, many health care institutions have persisted in providing high-quality care services and even introduced new technologies and new practices, including video diagnosis and treatment or visits, accompanying robots, and integration of electronic medical records into artificial intelligence prediction systems, so as to give patients the best options for a good death under such trying social conditions.

Hospice Care Abroad Has Science and Technology Work Together

The impact of Covid-19 on hospice care has not only limited the clinical environment due to social distancing and manpower shortage, but caused logistics teams like the administrative staff to work remotely and learn to use new technologies in order to cope with the pandemic. In this wave of the new normal, the world's hospice care systems have observed several new trends.



The first is the accelerated introduction of telemedicine. For example, The Centers for Medicare and Medicaid Services (CMS), a US federal agency, recently stated that it will review the flexibility of relaxing telemedicine regulations so that medical staff can use telecommunications technology to make up for the inability to perform face-to-face treatment or visits.

Next is the growing popularity of home medical care. Long before the outbreak of Covid-19, home care had already become a trend, but because of the pandemic, people are much more likely to feel anxious when entering hospitals or clinics, and thus, brought about an increased desire for further development of home care.

Lastly, the third trend is the sharp increase in demand for palliative care. Due to the limited treatment of Covid-19, symptom management has become an important aspect. In particular, many elderly people have faced psychological and social shocks due to strict isolation regulations, and they needed palliative treatment to provide cross-disciplinary assistance.

Deploying Multiple Technologies and Increasing the Efficiency of the Care Team

The past year has not only been a great challenge to patients and their families, but the hospice team also has had to respond at any time and make many adjustments. Many front-line caregivers have even received screenings three times a week just to ensure the safety of the care recipients. With the experience gained in this pandemic, the international hospice care system has learned to rely on the power of technology, including increased network bandwidth, electronic medical records, patient tracking systems, and etc., in order to improve the work flow and operational efficiency of the hospice care system, and therefore improve the quality of care.

As examples, the pandemic has required a larger amount of medical and nursing manpower, which results in a shortage of manpower for nursing care; and the work team is forced to work remotely. Therefore, many nursing care institutions in the United States have turned to online joint operating platforms to help frontline and logistics service manpower to work flawlessly as a team, assess the patient's condition in real time, and complete the task successfully. To make the most appropriate use of limited manpower, some institutions have even used artificial intelligence to conduct predictive analysis to identify patients in the most urgent need of care and attention.

Video Beyond Distance Not Alone at the End of Life

Among many assistive technologies, video is the most common one. Joey Milliken, the clinical director of St. Margaret's Hospice, a hospice care institution in the United Kingdom, said that he has learned a lot of valuable experiences from the Covid-19 pandemic, and one of the most important lessons is the need to deal with stress. When patients cannot see their loved ones and have no chance to talk with them, providing appropriate spiritual support becomes very important.



"Because face-to-face interaction is not possible, we use technologies such as video and audio interfaces to promote communication, helping patients and their families to discuss together and better understand what they need, what they value, and even the way they wish to die when their lives are about to come to an end," says Milliken.

The University Hospital of Chile, Hospital Barros Luco, has decided to set up special wards for the severely ill Covid-19 patients. These patients must also comply with strict regulations and wear protective clothing, but these wards have external windows. In addition to light, the patients can hear the sounds from nature outdoors. To create the best environment for hospice patients, medical staff use tablets to deliver voice or video messages from family members to patients, such as "Thank you, Daddy, for everything!" and "Dear Grandpa, please listen to this; it's your favorite song."

The medical staff of the hospital shared a particular case related to these special wards. In July 2020, when Enrique Boudon, a 94-year-old pneumonia patient, was seriously ill, his ten children had already said goodbye to him, but Boudon was still unable to leave peacefully. He continued fighting the illness and suffered greatly. Then Bouton's granddaughter revealed that he had played the trumpet in a symphony orchestra when he was young and was also a jazz fan. "So we took the tablet and played a song by the legendary jazz trumpeter Miles Davis next to him.

At that time, his hand seemed to move, as if he were conducting an orchestra.” Two hours later, Bouton passed away calmly.

Video and telemedicine have also played a very important role in home hospice. Kimberly Goessele, CEO of Alive Hospice, a nursing institution in Tennessee, USA, shared how the organization has used technology to bridge the gap between the medical staff and the sick. Due to the tornado disaster in early March 2020, roads everywhere had been severely damaged, and many patients could not be properly taken care of. The agency quickly deployed tablets to various communities, so that "not only could the team see the patients, but the patients and their families could see us, too. As a result, both sides felt relieved."

Under the adjustment of pace and the introduction of technology, the hospice and palliative care system of various countries have survived the most difficult year ever. However, with the pandemic still not contained, the budgets of care institutions have been tight, the cost of equipment and consumables have increased, and the labor market for care workers, which was originally short on manpower, has become even more limited. The turnover rate of caregivers has also risen again due to the pandemic. The reality is that technology is helpful in many respects, but still cannot replace all the work of hospice care.



The above-mentioned challenges will continue to test the development of global hospice and palliative care. It is expected that the world will receive more and more attention from public departments, advocacy groups, and even the general public in the future, to further construct a more complete system of hospice care, and thus, enabling more people to enjoy dying well.

PROF. CO-SHI CHANTAL CHAO

TAIWAN

Be brave in initiating changes and solving problems, but also involve team players.

Co-Shi worked as a clinical nurse, nursing instructor, and head nurse for ten years before becoming the director of the Hospice Home Care Programme at the Catholic Sanipax Socio-Medical Service and Educational Foundation in Taiwan. Her passion for palliative care inspired her



to pursue higher education in the field. In 1993, Chao graduated with a master's degree in oncology nursing and a Ph.D. degree in nursing with a focus on hospice and palliative care from Case Western Reserve University in the United States. Upon returning to Taiwan, she resumed her role as the director of the Hospice Program and gained a full professorship of nursing at National Cheng Kung University (Taiwan) in 2002. In the past four decades, she has cared for over 600 end-of-life patients, and her work has also helped establish Taiwan's palliative care service model. She was awarded the Special Dedication Award by the Ministry of Health and Welfare in Taiwan for her tremendous contribution to the service, leadership, education, and policymaking of palliative care. In 2011, she was named "Mother of Palliative Care in Taiwan" by the Taiwan Brilliant Women Survey.

Co-Shi set a visionary strategic plan for establishing palliative care in Taiwan through policy, education, service, and research. She is one of the important driving forces behind the Nature Death Act 2000 in Taiwan, which was the first Nature Death Act in Asia. The act honoured patient's right to choose hospice and palliative care and established their right to sign a "Do Not Resuscitate" order.

As a strategic and resourceful nursing leader, she understood that policy-making requires multidisciplinary collaboration. While caring for end-of-life patients and educating the next generation of palliative care professionals, she worked tirelessly to reach stakeholders involved in making the legislation. She advocated and lobbied for the act to superintendents of hospitals, administrators of health departments, and legislators from the Executive Yuan. Since the passage of the Natural Death Act, over half a million residents in Taiwan have signed the letter of intent, and the utilisation of palliative care services has also increased drastically. According to the 2015 Quality of Death Index published by the Economist Intelligence Unit, Taiwan ranked No. 6 internationally, and No. 1 in Asia. This great accomplishment would not have been made possible without Co-Shi's utmost advocacy and lobbying effort.



The greatest challenge she found of promoting palliative care was the taboo topic of “death” in Taiwan. Death was not commonly discussed among family members and even medical professionals. Through the death and dying education for healthcare professionals

and the general public, Co-Shi encouraged discussion around death, increased the awareness of a “good death”, and slowly changed the public’s perception and mindset on end-of-life care. The shift of culture takes patience, conviction, communication, and education, and she is truly a change maker through her actions and words.

She believes that patients are the best teachers, and they continue to inspire her to improve the quality of death in Taiwan. Nurses are the key players in providing palliative care, but support from the multi-disciplinary team is essential. Her recommendation to the next generation of nurses is that to make changes takes a lot of courage, wisdom, and love. Be brave in initiating changes and solving problems, but also involve team players who will help you to achieve your goals.

Related Resources

The Worldwide Hospice Palliative Care Alliance(WHPCA)
Palliative Care - Celebrating Nurses Contributions Report

Let's Sit Down and Talk

Lectures on Life in the Neighborhood

In the Hospice Foundation of Taiwan's lectures, a few paper cards and large prop banknotes aroused the senior citizens' interest in playing a game. They then focused on the topic of the Patient Autonomy Law and began to consider obtaining advanced medical decisions regarding medical autonomy, reluctance to be

a burden to the family, dignity, and etc., which could not actually be purchased in the game.



On a warm March day, a small shop in an alley in Shulin brewed the smell of strong coffee into the neighborhood. The bright yellow retro British telephone booth at the entrance attracted passers-by to stop and take pictures. Walking through the door revealed a tent, with exquisite camping lamps and camping tableware; outside the tent hung exquisite camping lights. The scene seemed to be moving people to the green mountains in an instant, making them want to sit on the ground and have a picnic.

"Ten Million Banknotes" Life Choice

This hipster coffee shop is the long-term respite care center of the Nursing Home in the Neighborhood program in Shulin; it is also a good place for local elderly to meet. A lecture was being held that day, and the speaker was Lin Yi-Yin, the CEO of the Hospice Foundation of Taiwan. She divided the elderly into two groups with each group given a huge NT10 million game banknote. The commodities available to be purchased included Medical Autonomy for 2.5 million, Spiritual Peace for 2 million, Not Being the Family's Burden for 3.5 million, and etc. Each item was

important and it was difficult to make a choice. The 10 million in the hands of the elderly was not enough to buy every item; still, they happily arranged the order of their needs and seriously took notes for future reference.

Incorporating the life and death issues (which most people in Taiwan tend to avoid talking about) into the game played in a relaxed and cozy atmosphere is a method adopted by the Hospice Foundation of Taiwan after its accumulation of experience from many previous lectures.

After the Patient Autonomy Law was officially launched in 2019, all people needed to do was complete the Advanced Care Planning (ACP) consultation forms and sign the Advanced Decision (AD). With the exception of terminal patients, those who are in an irreversible coma or a permanent vegetative state, with severe dementia or other diseases as permitted by the government, have the right to choose to refuse medical interventions such as life-sustaining treatment, artificial nutrition and fluid feeding, and to say goodbye with dignity in the way they want. The Patient Autonomy Law can also enable medical personnel to have a clear basis when performing the medical treatment on patients with full legal protection.

However, the general public at large is still unfamiliar with the content of the Patient Autonomy Law and do not know where to sign AD. In view of this, the Hospice Foundation of Taiwan decided to enter the neighborhoods of the community and launch publicity lectures to let more people understand the spirit of advanced medical care and discuss with relatives and friends how to "say goodbye" with a healthy attitude.

"The topic of today's lecture is The Patient Autonomy Law. The law is difficult to talk about and hence accept. To make the elderly listen to it more attentively, we came up with the bidding game, which uses concrete props to lead the elderly to measure what choices must be made at the end of life to achieve the good death they want," Lin Yi-Yin said.

To make the game lively and interesting, paper cards and prop banknotes are not only eye-catching and easy to carry, but can also be passed out in different amounts as needed based on the number of people in the venue. The simple and easy-to-understand paper cards with the prices guide the elderly to consider the importance of medical autonomy.

Education with Fun

Experience the Spirit of the Patient Autonomy Law



Although many lectures have been received well, not every lecture has gone so smoothly. Lin Yi-Yin recalled a time when she went to a rural area in Nantou to hold a lecture at a community care center. Among the elderly who attended, there was a particular couple. The husband kept interrupting the lecture, while the wife kept shaking her feet restlessly. At first, Lin Yi-Yin was worried that the wife was not feeling well, but the staff said she was OK. After the lecture, she asked the staff at the center about it, and found out that the wife was very afraid of discussing life and death issues and that she had been forced by her dominating husband to come.

"If I had known about her fears and worries beforehand, I would have talked about the topic in a different way." However, this experience can also help the frontline staff to understand that "even in this age of advanced information, there are still people who can be so afraid when listening to this topic that they don't want to touch upon this topic emotionally," Lin Yi-Yin said.

After accumulating extensive experience from many lectures, the Hospice Foundation of Taiwan gradually adjusted the content of lectures. For example, using games to start the topic so that the elderly grow interested in playing the

game and can better focus on the topics when the slides are presented in the second half of the lecture. The result has been more success in helping them think about whether they could obtain key items, such as medical autonomy, reluctance to be a burden to the family, or even dignity through advanced medical decisions.

In the past, the Hospice Foundation of Taiwan had played board games as an introduction to the lectures, but colleagues noticed that some elderly were very introverted and could not assimilate into it, which led to poor results. Therefore, a fun bidding game was created to replace the board games so that the importance of advanced medical care could be better understood.

Help You Overcome the Fear of Death



In the lecture that day, the 70-year-old Mei-Chun participated in an event organized by the Hospice Foundation of Taiwan for the first time. She had always seen death as a taboo topic. Even though her daughter, who was a nurse, told her about the Patient Autonomy Law, she still resisted to understanding it. That day was the first time Mei-Chun had heard about it from someone other than her own daughter. Through a simple game, she deeply realized that leaving with dignity and not becoming a burden to her family was what she wanted most. In addition, the scope of medicine is wide, and

it is necessary to consult with professional medical personnel and understand the meaning of the Patient Autonomy Law to ensure that when the last moment comes, a person can say goodbye in the preferred way.

Completely different from Meichun was Deng-Feng, who was very concerned about issues such as hospice and palliative care and medical autonomy. Deng-Feng's husband spent his last stage of life in a hospice ward, which provided the elegance, completeness, and dignity she pursued. So after the Patient Autonomy Law was officially passed, she immediately made an appointment for consultation and signed AD while accompanied by her daughter, who served as a witness. Her daughter, who was only in her 30s, also signed AD the same day after she grasped the importance of advanced medical care.

Shan-Bi, who had suffered from a serious car accident and ALS (Amyotrophic Lateral Sclerosis) in her life, already faced the dramatic change in life calmly because her family's concept of hospice and palliative care was established early. In addition, her grandmother, who was suffering terminal cancer in 1962, said goodbye to her family gracefully under a hospice treatment. After many years, when the medicine was no longer effective, her father also decided not to use invasive first aid, but to let life reach its end naturally.

Draw a Perfect Period for the End of Life

The Hospice Foundation of Taiwan has always been actively involved with the public. Besides regularly inviting celebrities to shoot public service advertisements and launch online promotional videos, it also hopes to listen to the voices of the people in a direct approach, such as providing online promotional videos, illustration books with pictures and texts, books, two annual newsletters, entertaining board game teaching aids, and DVDs. By means of a variety of promotional materials, the Hospice Foundation of Taiwan closes the distance with the public.

Lin Yi-Yin said that after each lecture, she would collect feedback from the elderly as a motivation for improvement of the foundation. Faced with elderly from different backgrounds, each of whom has a different understanding of life and death, the Hospice Foundation of Taiwan's responsibility is to spread the concept through various channels. As long as time permits, she prefers to have case discussions with the audience, because she believes "only by solving the problems in the mind can the concept be brought into the heart."