



Hospice
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Since 2018, approximately 300,000 more citizens will reach age 65 every year. Among these elderly, 12% is expected to be disabled, which equates to 30,000 elderly, who will require long-term care services. This will be a huge challenge to the caregiver workforce and the caring system.

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The Integration of Long-term Care, Home Care and Palliative Care in Taiwan

Dr. Jui-Yuan Hsueh,

Vice Minister of the Ministry of Health and Welfare of Republic of China (Taiwan).

Background

According to the WHO, the proportion of a society's population that is comprised of persons aged 65 and above is called the "aging rate." When this aging rate exceeds 7%, it is an "aging society;" if the rate surpasses 14%, it is an "aged society;" and if over 20%, it is a "super-aged society." In Taiwan, senior citizens above 65 years old exceeded the 14% threshold this year, which means Taiwan has officially become an aged society. Furthermore, it is anticipated to exceed 20% in the coming eight years to becoming a super-aged society.



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It is predicted that in 2030, citizens above 65 years old will increase to 2.16 million while, at the same time, the number of workforce and newborns will decrease to 1.96 million and 0.37 million, respectively. The change of family structure and how these elderly will live deserve considerable attention, especially as data from the last decade indicate that the birth rate 1.13, and the average family members decreased from 3.5 to 2.7.

Based on the Annual Report of Senior Citizen Condition Survey 2013—published by the Ministry of Welfare and Health R.O.C. (Taiwan) —more than 72.7% of the elderly live in flats or detached/terrace houses without elevators. Meanwhile, only 12.7% live in elevator-accessible buildings and the rest 14.6% of elderly live in single-story houses. Furthermore, elderly who live with children, grandchildren or parents has dropped from 29.8% in 2009 to 25.8% in 2013; and elderly who live alone has risen from 9.2% to 11.1%.

Asked if they are willing to move in to longterm-care institution, it is clear that those elderly between 55 and 64 years old are more willing than those 65 and over. Apparently, economic independence and educational level are both important factors, especially as their economic resources depend mostly on their children and grandchildren, thus limiting their options.

For the elderly above 65 years old who are disabled and require care services, there is a total of 737,000 people in 2017. Of these, 41% are being taken care of by family members, 32% by foreign caregivers, and 12% by institutional care. Only 15% receive community and home care service, which are supported by the government's Long-term Care 2.0 policy.

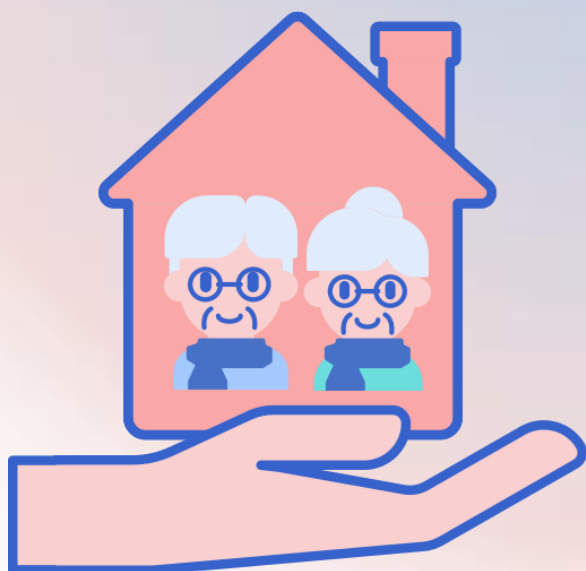
From the above evaluation, Vice Minister Hsueh has made the following conclusions: (1) there is a growing demand of care but insufficient workforce for it; (2) there are housing conditions that restrict the elderly from social participation and ease of seeking medical assistance; and (3) there is an increase of solitary living and economic dependence among the elderly.

Current Policy

Taiwan has legalized and regulated palliative and hospice care and long-term care service, which started in 1995. The current two main policies are Long-Term Care 2.0 Policy and the Hospice Palliative Act.

The goals of the Long-Term Care 2.0 Policy are to prolong healthy life expectancy, maintain life functions so as to reduce the bed-ridden period, and respect the quality of life. These three goals aim to lessen the demand and burdens of caregivers while at the same time to protect the dignity of elders and their quality of lives.

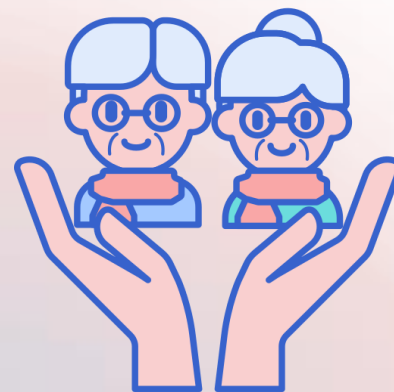
The eligibility for Long-Term Care 2.0 Policy include functional limitations and age, and has expanded to people aged 50+ with dementia, people aged 65+ with frailty, and disabled people regardless of age.



In the last three years, resources for home-care services and day care centers have grown 41.2% and 11.6%, respectively (compared to 2017). Transportation services have grown 91.7%, which can effectively assist with the elderly's transportation, and significant growth of disability prevention has risen to 94.4%.

As for Hospice and Palliative Care, based on July

2018 statistics, the current palliative services can serve 50,000 terminally ill patients yearly. These services include 70 hospitals with a total of 804 beds, 114 home care services, 151 share-care services, and 289 community care services. The percentage of terminally-ill patients with cancer who receive palliative care has also increased from 29.9% in 2011 to 58.7% in 2016.

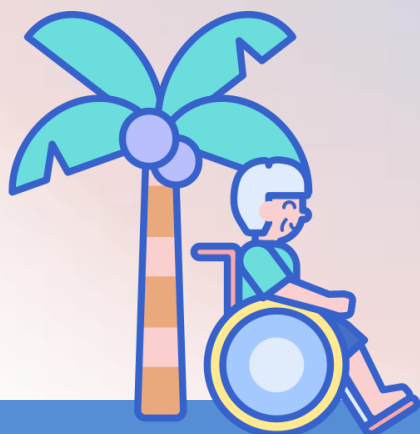


Challenge

Long-Term Care 2.0 Policy includes a very wide range of services, some are provided by NPOs like respite services, community care centers, day care/home care centers, transportation services, and meal services; and some are provided by healthcare systems like chronic diseases management, home care/rehabilitation, LTC facilities and discharge planning. The big challenge that lies ahead is how to integrate services prodded by NPOs and healthcare systems. The Ministry of Health and Welfare has specifically established the Department of Long-Term Care to focus on this challenge.

Worldwide, Japan, Italy, Germany and Finland have all become super-aged societies, and the transition periods for each were 11, 19, 36 and 21 years, respectively. With similar cultural backgrounds, Japan's experience in policy-making, system buildup, and resource integration are worthy of reference for Taiwan.

In conclusion, as Taiwan is now heading into the second decade of long-term care development, the current system still needs to be reviewed to ensure the system can face the challenge of the aging population and the limited workforce resources. From a policy making perspective, how to connect the two existing systems of health care and long-term care, how to integrate with ongoing various care plans under one scheme, and how to build up the continuity of community care services are the Ministry's current tasks.



Calm Approach to the Last Station of Life

Written by **Wen-qin Liang** and translated by **HFT Secretariat**

For people living in rural and remote districts, going to hospitals can be difficult, especially for matters of life and death when the need of palliative care is desperate and the scarce resources make it even worse. Puli Christian Hospital (“PCH”) was established to serve people in remote districts, and it started providing palliative and hospice care services twenty years ago with its palliative team. In 2017, PCH set up its palliative and hospice ward to provide more comprehensive care for Nantou area residents.



“When I started to serve in Puli Christian Hospital in 1993, palliative care was an unfamiliar concept not only to the public but also to medical professionals,” recalled Dr. Cheng-Sheng Zhang, who was asked how palliative and hospice care was being set up and promoted.

It all began with a call in 1994, when an old lady with advanced cancer wished to move back to Puli from the United States and die peacefully in her hometown. Her family members inquired Puli Christian Hospital for home care resources, and this call somehow was transferred to Dr. Zhang’s phone extension. At that time, PCH still had insufficient manpower issues and had no precedent of house calls and no idea how to charge for house-call service. Dr. Zhang said to himself that patient’s needs should be prioritized above everything else, and so he drove his car to pay personal visits and provide constant care until she passed away.

That happened to be the time when Hospice Foundation of Taiwan (“HFT”) started promoting palliative care and providing classes for professionals. It was not until Dr. Zhang read about HFT that he understood what he did for the old lady was called palliative care. He registered for HFT’s training class and was determined to provide more palliative services to people who need it.

It was not long after that the government started to promote the palliative care pilot project. HFT also sent a team to visit PCH and encouraged it to set up a palliative team and provide palliative care to the neighboring area. In 1995, PCH appointed Dr. Zhang as the physician to lead its palliative team to start providing home care services.

With insufficient manpower, PCH insists on serving people and providing palliative care service. The covered areas expand from Puli to remote districts like Guoxing, Yuchi, Shuili, Xinyi, Rea'ia and more. PCH is the first to start providing palliative care in the Nantou area, and has been doing so for more than 20 years.

“Though the shortage of manpower hasn’t been solved, our nursing staff pays home visits constantly, and has exceedingly surpassed the NHI cap of 45 visits per month. As long as patients need us, we shall continue to visit them,” said Dr. Zhang with affirmation.

From Palliative Home Care to Ward Care

Since PCH started providing palliative home care service, the palliative demand in the area has been noticed. The setup of a palliative ward seems to be inevitable. All the relevant assessments have also been carried out to evaluate the possibility. However, “manpower resources and cost of the facility and place are all realistic concerns. Compared to regular medical care, palliative care requires higher quality with higher management cost and higher demand for staff power. This is why the setting up of a palliative ward has been under constant evaluation,” Dr. Zhang spoke openly.

As palliative care matures over the years, palliative home care cases have also increased by nearly 100 per year; demand for palliative shared care has also increased. Of note, the nursing home ran by PCH has made efforts in combining palliative care and long-term care into its services and those efforts have been awarded with the National Biotechnology and Medical Care Quality Awards, and also the SNQ Symbol of National Quality – Safety and Quality. “Setting up a hospice ward felt necessary and right, so we started working on it. The hospice ward was established in 2017,” said Dr. Zhang, who has been asked by the hospital administration whether he is willing to take over the palliative care department again and lead.

The shortage of nurses has remained a tough challenge when it comes to providing medical services in remote districts. “The original goal was to open 12 beds, but as the staff turnover rate is high in rural and remote districts, qualified



candidates are rare and unable to meet the nurse/bed ratio of 1:1; thus the number of beds has reduced to 5 beds,” said Bao-chu Lai, the Nursing Supervisor of PCH. Once PCH recruits enough nursing staff, the ultimate goal is still to offer 12 beds.

Once Stabilized, Patients Return Home

While most people assume that the palliative and hospice ward is a place of no return, more than half of the patients who check in at PCH actually return home once they are stabilized.

“This is one of the purposes of patients to choose to stay in the hospice ward. When patients check in, we ease their acute symptoms and refer them to the home care team to take over once they are stabilized,” said Nursing Supervisor Lai.

Dr. Zhang added, “What we hope to provide is comfort. When we go to the communities to promote palliative care, we always explain palliative care to the public in a very direct manner. We tell them palliative care does not mean giving up, but means to ease your pain and symptoms, and maybe even to help you live longer.”

For most patients living in the cities, once they check in to the hospice ward, they would prefer to approach their end in the hospitals. However, for people living in rural districts, they prefer to revert to their origins and go back to their familiar houses, with their family members and in their neighborhood. This is why the palliative team of PCH will endeavor to support patients’ condition in the shortest time possible to reduce hospitalized time. Patients’ family members will also be taught how to care for advanced patients, especially what should be expected and cared for at the end of life stage, so that both can feel ready and focus on that moment rather than panicking.

Comfort of Mind and Soul in the Fullness of Life

When patients are at the end of their lives, family members are often emotional and find it hard to accept. Some even relate the hospice ward as a place of dying. The palliative team will typically explain the purpose and aim of the hospice ward and introduce its facilities to help family members understand and be consoled. Hui-chen Chiang, the nurse head of PCH hospice ward further explains, “We pay full attention to assist and care for mental consolation; we also remain connected with regular visits to provide grief and bereavement care, and to help during the family’s grieving period.”

Chih-kai Yang, director of PCH social service department, added they prefer to talk to patients and their family members to offer counseling and spiritual care. “It is probably because of the rural/city differences, patients here are mostly local elderly, who are not

comfortable at expressing their feelings. We help them focus more on how much they are being loved and to love themselves. They are not burdens just because they are sick, but they are loved dearly. This helps patients feel calm and fulfilled. Additionally, family members who care for patients have also a share in the distress and pressure. As a result, the palliative team not only cares for the patients but also for their family members.

Director Yang also shared a case story with us. When Director Yang was communicating with an old lady who suffered from liver and renal dysfunction, he discovered this old lady had been referred from many hospitals and hadn't been home for quite some time. Though her husband accompanied her to the hospice ward, deep down in his mind, he was still looking for other medical services to revive her. The lady showed distress and was not willing to cooperate. Noticing her discomfort, the PCH palliative team members started to communicate with her husband for her longing to go home. Finally, the husband agreed to take her home.

Later Yang heard from the family that once the old lady returned home, she felt safe and relaxed, and enjoyed a long sleep. A few days later, she passed away peacefully.

PCH palliative team's heartfelt care has touched many hearts. "Many things we use to care for patients have been donated by patients' families, such as the essential oils for patients' massages, the piano played for them, and the car driven on visits. Some family members have even signed up for volunteering," said Nursing Supervisor Lai. These stories of helping patients' lives have all become the driving force and motivation to the hearts of the PCH palliative team members, who are encouraged to continue serving fervently.



May Sorrow Fade When Hearing This Song – Music Therapy

Written by **Xi-yi Tu** and translated by **HFT Secretariat**



Though Yu-hsuan Liu has been serving in the hospice ward using music therapy for years, many patients still don't know how to address her position except as "the singer." Liu doesn't mind because she only cares about whether she has helped these patients feel better and become more complete in their last stage of life.

Dive Unexpectedly into the World of Music Therapy

When Liu was 5 or 6 years old, she already played piano and flute competently. With her talent, it was no surprise that she enrolled in a special music class during high school.

Her passion for music was undeniable, and she desired no spotlight on the stage. Not wanting to become an artist or a music teacher, she was confused about what she should do in the future except to continue in the area of her passion for music.

She overheard from a senior student the term music therapy, and learned from Jui-ling Hsiao under her teacher's recommendation. At that time, Jui-ling Hsiao had just completed her music therapy degree in the United States and started to serve in the Kaohsiung area. That was how Liu started to learn what music therapy really was through her observations.

Many children they served were stricken with severe diseases, and though it has been ten years already, she still remembers a child with cerebral palsy who had no intellectual disability, but instead had great difficulty walking. With support of a walking aid orthotic, the child courageously struggled to march out with every little step.

"Children listen to our music or drumbeat to follow the little footprint marks on the floor and stop when the drumbeat stops." It looks like they are



playing a game, but in fact, this is rehabilitation designed to be fun in order to motivate children. Instruments are also situated in the corners of the room, and once children make it to that corner, they are allowed to play the instruments as they like.

“This child improved from 2-3 steps at a time to 3-4 steps, and it took 10 classes for him to finish all the footprint marks in a single attempt.” Liu believes in the value and results that music therapy can bring to children with severe diseases by personally witnessing the improvements of many such children; as a result, her heart is filled with a sense of mission and accomplishment.



With all the times she has spent with her young patients, her career path also emerged. “Compared to those who wish to learn an instrument professionally, I am led to believe that these patients with severe diseases need me more,” Liu said.

Music Is a Bridge, and the Music Therapist Architects that Bridge

Music therapy is still unfamiliar to the general public. When Yu-hsuan Liu completed her music therapy degree in America and returned to Taiwan for employment, she took the initiative to knock on many doors to seek opportunities and even hosted many free lectures to introduce music therapy. After six months of demonstrating the benefits of music therapy as a volunteer, she finally received a job offer from the cancer center of Cheng Kung University Hospital.

There was a couple she met in the cancer center that she still recalls vividly. “The woman who was in her 50’s was sick, and along with her husband, they appeared to be a very reserved and traditional couple with minimal displays of affection.” Liu visited the woman often for chats, and listened to her complaining about her husband. “I really wish my husband could speak lovingly to me more often, even to the degree that will make me feel embarrassed, but he is just not like this,” said the woman.

Hearing the distress, Liu knew she had a mission at hand. It was clear to the outsider that her husband cherished and loved her very much, but his temperament made it difficult to speak words of love. Nevertheless, Liu prepared the lyrics from a famous love song – “The Moon Represents My Heart” – by removing most of the lyrics and inviting him to fill in the blanks with his memories. Eagerly, the husband spent half the day on the task.

When Liu next visited the woman, she asked if she knew what her husband had been



doing secretly. Dismayed, she replied, “There is not much he would do.” That was when Liu picked up her guitar and started playing the melody of “The Moon Represents My Heart.” Knowing the husband would be shy, she took the liberty to start singing the song until eventually he joined and sang his personalized lyrics in a whisper as tears flowed down his cheeks. In response, his wife shed tears of great surprise and joy, and intently cherished this moment until the very last tune.

Effective as the song was, there was not a single phrase of “I love you” or any sappy romantic word in his personalized lyrics, which simply included descriptions of the ordinary routines of life. “He praised her cooking, especially a certain dish that he really likes. These bits of memories represent his love and gratification to her,” Liu said happily.

Interestingly, this song also brought the husband closer to their children. As Liu witnessed: “Their children had always thought their father took their mother for granted by not cherishing and caring for her enough. It was not until they heard him sing this song that they realized their father’s subtle but deep affections. If music had not been welcomed into the wards, they might not have experienced this alternative way to express their feelings for each other.” Thus, music therapy can truly ease respiratory symptoms, pains, and also offer invisible psychological support. “Music is like a bridge, which links people’s hearts in an open manner, and the music therapist is the architect of the bridge.”

Caring Not Only for Patients, but also for Families

In the hospice ward, Liu accompanies the families as well as the patients. One time, she saw an 18 year-old girl grasping her mother’s hand tightly for fear of forgetting her mother’s love and presence in the years to come. Her mother was in a coma and breathing her last breaths. Liu then retrieved a sketch pad and made a hand print of the dying mother, so that the daughter could always remember her mother by looking at the hand print.

Another time, Liu accompanied a mother who was about to lose her child, and they recorded a loving



song for the child. Later, Liu added something special to the background of the song because “her child was unable to speak in his final days, so I’ve added her child’s heartbeat in the song.”



Dying well for the patients and living well for the families—this is her firm belief. She hopes her music can open the invisible door between patients and their families, and continue to grow in empathy as she comprehends their unspoken needs. Such hopes are being realized as confirmed by a 35 year-old engineer who never interacted with her but spoke with his remaining strength saying, “although I really don’t like to talk, but I really appreciate what you are doing.”

“When people think of the hospice ward, they think of a place for the dying. In the hospice ward, we care for one’s life in many aspects. Though curing one’s disease is no longer the main focus, we emphasize one’s physical, psychological, and spiritual comfort. The entire palliative team—hospital chaplain, music therapist, social worker, psychiatrist, and volunteers—all give the best care they can to patients and their families.”

In a lecture Liu was giving, a student once commented, “The hospice ward must be a very quiet place!” She smiled and corrected the student, “Not at all! In fact, hospice wards can be super chatty!”

Liu is disappointed that although palliative care has made significant progress in Taiwan, there are still many elderly who associate fear with the word hospice. “Sometimes patients pass away quickly when they arrive in the hospice; however, I really want the public to know that palliative and hospice care is not only for patients in their very last moments of life. Instead of viewing the hospice ward as a terminal for a one-way trip, it really is a place for patients to prepare. Palliative and hospice care professionals are devoted, goal oriented, and focused. Just like Liu said, “Our mission is to ensure patients die well and their families continue to live well.”



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