Hospice
Foundation of
Taiwan

HFT Newsletter

Forever Love, Endless Care

October 2022

HEALING HEARTS & COMMUNITIES
WORLD HOSPICE & PALLIATIVE CARE DAY 8 OCT 2022

Image adapted from pch.vector on Freepik

The Dilemma of Family Caregivers — Support Is Always There, Accompanied with Gentle Support

more >

Self-care for Caregivers — Support Is Always There to Climb Out of the Valley

more >

Long-lasting Palliative Care — Make Good Use of Resources and Ignite Energy for Self-care

more >

Heavy Burdens Weigh Down Front Line of Hospice Workers — Professional Intervention Provides a Strong Pillar for Palliative Caregivers

more >

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

The Dilemma of Family Caregivers — Support Is Always There, Accompanied with Gentle Support

The two words *palliative care* are easy to say, but it is actually quite a difficult task to complete. For family caregivers who have not received relevant professional training, they have to undertake the challenges brought about by this change, and at the same time, knowing that their normal routines will have major upheavals.

Whether it is the physical burdens, financial difficulties, or psychological pressures, everything is placed on the family caregivers, so that they have to remain afloat while being blown and swaying back and forth between *expecting* relief—such as when their loved ones finally pass—and *fearing* relief—such as when loved ones' condition improve for the near future but still requiring constant attention and care. Are these seemingly intractable problems really unsolvable?

Meeting Needs through Active Caring

Whether in the ward or at home, Lin Chun-Lan, the chief nurse of the hospice team at Saint Mary's Hospital Luodong, identifies inescapable exhaustion as the most common suffering for family caregivers.

"Whenever a new case is transferred to a hospice ward, we ask the family members what assistance they need. Most people tell us they have not had a good night's sleep in a long time," says Lin Chun-Lan. She further observed that under the societal norm of low birthrate and dual salary structure, the burden of family caregivers is often placed upon the same person. As such, it is more common for the elderly to take care of the elderly *and* for the elderly to take care of the young. Especially as terminally ill patients encounter unpredictably changing conditions, the caregiver has to adjust and be alert every second, and thus, the result is many sleepless nights and constant fatigue.

In this regard, what hospice wards can do to help is to take on and tackle this burden along with the family. Lin Chun-Lan assures the family members, "Our nurses on the night shift will take good care of your family member for you. You can sleep well at night and come back in the morning with the strength you need to continue taking care of your family member."

One can still receive a night of respite in the hospital, but how about when it is at home? Lin Chun-Lan just smiled slightly and answered, "The home hospice team must be sensitive enough to detect the needs of the caregivers, and ask social workers, psychologists and other professionals to intervene and assist when necessary."

However, the team also found that most people in non-metropolitan areas are simple people, and that they are reluctant to use most of the resources provided by either the long-term care 2.0 or social groups. Jian Shih-Ting, a shared-care nurse, said with a sad smile that it is also one of the main reasons that make these family caregivers fall into the abyss of exhaustion. "When we mention it, they always say that they don't need the resources, and that the resources should be given to those who need them more. However, according to our assessment, they *are* the people who really need them."

Physical and Mental Exhaustion from Long-term Care

With the growing popularity of home hospice care, more and more family members are choosing to bring hospice care from the hospital to their homes. In order to allow patients to return home with peace of mind, the home hospice team provides additional, meticulous care. Lin Chun-Lan remembers the time a family brought the dying patient home, and when they realized that a needle had come off, they starting panicking. To comfort the family, hospice team members drove to their home. "It took two hours to go up the mountain, and so, the return trip took a total of four hours just to go back and forth. That’s a lot of time to help reposition the needle and calm the family."

Regarding this issue, MacKay Memorial Hospital’s home hospice team indicated that the home hospice team is indeed the strongest physical and psychological support for family caregivers. In addition, it also takes the role of detecting difficulties before they arrive. With the team’s systematic methods, they will put in a lot of time and effort during the first interview, piecing together the family profile of the case from the questions and answers in order to figure out the proper assistance they can provide.

"If it’s the symptoms of the patient's own disease, we will ask physicians to assist in adjusting medication or installing related nursing machines. If there are care-related problems, the nurses will assist in teaching. If it’s an issue of finances, we will ask social workers to assist in finding resources. And if it’s related to psychological problems, we will ask the psychologists for help,” remarks the senior nurse Xiao Zi-Yan, who has devoted herself to home hospice for many years. She also explained the various pressures facing the family caregivers and their possible solutions. However, she also admitted that more often than not, things are not always so simple to resolve, especially when it comes to psychological stress.

"Especially in caring for non-terminal cancer patients, because the course of the disease may be relatively long, the caregivers have to live with life restrictions and psychological pressure for a long time." Xiao Zi-Yan analyzes that when all the responsibilities of caring are on the same family member, the caregiver not only loses the freedom to live his/her life, but may also have to sacrifice work and even face alienation in relationships. As time goes on, they can't help but ask themselves, "How long will it be like this?"

There was once a wife who was taking care of her husband, who had suffered from colon cancer for many years. The physical and mental exhaustion brought about by the long-term care almost devoured her. She told Xiao Zi-Yan that sometimes when she heard the doctor say that an examination should be done, she would feel scared; not so much as to hearing the bad news, but to be told that the course of the disease might be improving.

When she spoke, her soulless eyes looked at Xiao Zi-Yan wearily, saying, "This would make my job of caring for him become even longer when I often secretly hope that he can go to heaven soon."

The Predicament of the Elderly Caring for the Elderly

Xiao Zi-Yan has seen the exhaustion caused by long-term care, and among the cases under the care of another nurse, Li Yi-Yun at MacKay Memorial Hospital, she shares a particular case regarding early-onset dementia. It has been 16 years since the onset, and the patient has been bedridden for nearly 10 years and meticulously cared for by her husband. Although it is also long-term care, Li Yi-Yun sees a completely different scenario.

"The man is almost 80 years old, and even though he has a foreign domestic helper, he almost always takes care of his wife himself," Li Yi-Yun said with admiration. She had known this couple for two years already, and under the husband's attentive care, the woman had never received any type of infection. “Whether urinary tract infection, or respiratory infection, or other types of infections, it never once happened to her! Even when the weather changed occasionally, and she caught a slight cold, her symptoms were quite mild considering her condition.”

Every day this husband brushes his wife's teeth. Occasionally, without the usual cooperation of his wife, it could take anywhere up to 10 or 20 minutes to complete the oral cleaning, yet they have never heard the husband complain. On a daily basis, he is consistently patient no matter what the situation. For example, one day when he was brushing his wife's teeth, he suddenly noticed that half of her tooth had fallen out, but he couldn't find it after searching for it in her mouth and rummaging through the bed. That’s when he panicked, and rushed to bring her to the hospital by the rehab bus for a check-up, simply because he was worried about what could happen if the tooth was unfortunately stuck in her esophagus or respiratory tract.

Everyone saw clearly his love for his wife, so when he proposed that unethical proposal to Li Yi-Yun, Li Yi-Yun was almost at a loss. He asked, "She is now fed through a nasogastric tube. If I don't force-feed or if I remove the nasogastric tube, will she starve to death?" Although he presented it as a question, he actually knew the answer already.


Image by Freepik

After in-depth discussion and understanding, Li Yi-Yun realized that the old man has reached an advanced age and his own health is gradually getting worse. He does not want to burden his two daughters abroad, nor does he want to leave his wife in a tragic situation of poor care. He has obviously given it some thought for a long time so he was thinking, maybe when he becomes unable to take care of his wife, he would have to starve her to death first.

"Are you willing? You love her so much," Li Yi-Yun responded.

Unable to smile, the old gentleman replied with a lonesome voice, "It is because I love her so much that I can't bear to see her not being well taken care of. I think one day, I will have to do something."

Support Continues to Accompany Family Caregivers

Even now Li Yi-Yun is still trying to communicate with and assure the elderly gentleman, "Either way, we will definitely accompany you and your wife all the way to the end."

For the home hospice team, giving patients a sufficient sense of security is always the first and most important thing. Li Yi-Yun said with a smile, "As long as they don't feel alone and the support continues to help them, then they can pick up strength along the way and continue to move forward."

Image by DCStudio on Freepik

Therefore, when taking care of these family members, hospice team members need to be both active and proactive. While discovering and solving problems, they also attempt to predict what may happen in the upcoming course of the disease, so that family members can be more prepared in advance regarding palliative care and psychology. At the same time, they provide a 24-hour dedicated line so that family members can find someone for comfort or assistance at any time.

"We have to take care of their needs and even their uneasy emotions at any time," says Ou Pei-Yi, a nurse at Saint Mary’s Hospital Luodong. She once encountered a primary caregiver who was always worried, saying, "If the mother was awake, he would be very worried whether he was be able to take good care of her; but if the mother slept for a long time, he would also worry about her. During these times, he often reached out and called us for support."

"We didn’t deny him, but affirmed his emotions and told him what the next step was and what to do," explains Ou Pei-Yi. Looking at such frequent emotional tossing with empathy, she concludes, "The patient's condition was terminal, and it’s quite natural and normal for the family to be in such an uneasy state.”

The life pressure and psychological adjustments faced by family caregivers often require long and substantial assistance. However, as time progresses, whether it is the governmental central policy or local related groups, the support systems deployed by them have blossomed everywhere. In the meantime, the training of the medical teams has also made the provided assistance more diverse and more comprehensive. Thus, the future looks bright as we look forward to providing adequate support of family caregivers with stability and tenderness.

Self-care for Caregivers — Support Is Always There to Climb Out of the Valley

The pressure from society, environment, and ethics often makes caregivers drift into an inescapable, deep valley. However, whether it is professional psychological support, family understanding, or assistance from social resources, the venues for help have never been far away, but are waiting for those deep in trouble to draw near.

Whether it is in the long-term care center or in the field of hospice, when facing the extended course of disease and the anxiety regarding end of life, apart from the patients themselves, the people most affected are the personal caregivers. They include family caregivers, professional caregivers, such as medical teams or home service providers, care workers, and etc.

In the physical and mental pressure resulting from exhaustion and frustration, only by seeking the solution and support of self-care can one regain inner strength in the process of palliative care.

On-site Care Service Impact of the Professional

Some time ago, Lo Hui-Chun, a counseling psychologist at Mackay Memorial Hospital Counseling Center, saw a post from a nurse in the hospice ward on a social networking site; she wrote, "Today, we sent another six patients to heaven."

Lo Hui-Chun says, "This is actually the daily life in the hospice ward." Talking about these partners who are working together on the front line of medical care, it is not difficult to part ways. At such a highly intense worksite where one may face death every day, one must have a strong psychological quality in order to contend with the endless, traumatic impact day after day.

Lo Hui-Chun believes that the imbalance they face bears the brunt of the collision of professional role values. According to his analysis, because most of the concepts given by medical education today are to help patients move towards recovery, after staying in the hospice ward for long enough, the clinical team cannot help but begin to doubt the meaning of self-existence. Then, a strong sense of guilt and self-blame arises, which finally can lead to burnout. Once this occurs, some will choose to stay away from the hospice site, while others clam up their emotions tightly.

The same situation also exists in the caregivers in the field of long-term care. Faced with the gradual incapacity or deterioration of the long-term care patients, the chronic fatigue caused by long-term wear and tear and physical and mental exhaustion makes them feel powerless and helpless. There is even something known as *vicarious trauma*.

At this critical moment, what hinders is neither that they have no way out nor is it difficult to seek help from counselors; but rather, the word *professional* rubs away on them. On the one hand, they know themselves to be hardworking professionals, and yet, they are also caught in great struggle and conflict. On the other hand, they want to maintain their professionalism, worried that asking for help might bring about unfavorable judgment and criticism from others.

"Therefore, even if they know that they should seek professional help, they will hesitate and think it over for a long time," explains Lo Hui-Chun with sympathy. The plight of professional caregivers is more than this as Lo Hui-Chun suggests, "The medical and nursing community are helpers in a broad sense. Because it is a human being they are taking care of, there will inevitably be emotional connections. In particular, nurses stay with patients and their families almost 24 hours a day, so they are the closest to patients. Naturally, they will hear many personal and family stories.”

He once met a nurse who was determined to devote herself to hospice care since she was a child. In the process of caring for a particular patient, whose condition, family situation, and even age were similar to her own mother’s, she was reminded often of the heartbreaking experience of her own mother’s death many years before. The deep-seated trauma brought emotional swings and even gradually interfered with her work.

Self-Care Recharges Oneself

Facing the deep suffering of these clinical front lines, Lo Hui-Chun provides sincere advice, "Bravely seek professional psychological support. After all, helping people consumes energy, which is also called *emotional labor* in medical research.”

Lo Hui-Chun points out that dialogue is actually a way to open up for self-care and self-acceptance. Through the guidance of a psychologist, people can face the topic and issues of life and death, and find the most appropriate solution through clarification and understanding.

"The nurse who remembered the pain of his mother's death finally chose to leave hospice care. After moving to other wards, she was able to enjoy her work more," says Lo Hui-Chun with a smile. He suggests that leaving the hospice ward may be one of the solutions for a small number of people, but there are more clinical front-line nurses, who regain their enthusiasm for hospice and life with the assistance of professional counseling.

For professional caregivers whose emotions have not yet affected their life and work, he suggests that they must maintain a balance between life and work and retain a sense of self-care.

"Many people become stuck in professional roles, or resort to self-blame thinking 'I should be able to do better.' At the same time, they forget that they are also human beings," observes Lo Hui-Chun. People often forget that professional caregivers are also human, and need to be treated with respect.

Lo Hui-Chun acknowledges, "Only when one's self-awareness is relaxed can one be kind to oneself and to others." He thinks that not only should caregivers look at their own work with a more forgiving attitude, but in the clinical front line filled with enormous pressures, they must also be aware that life is not just all about work. He suggests, "Sometimes through yoga, deep breathing, going on a trip, or other activities, one can gradually realize what one’s personal inner needs are in the process of finding relaxation."

Only when the *self* is freed from work, the expectations placed on *self-care* can be realized concretely. Lo Hui-Chun always believes that professional caregivers work by giving a part of their own lives away to others, and because of this responsibility, they are fully committed to burning the wick of their lives, which can easily lead to burn out. Therefore, in terms of self-care, they need to supplement what they give to others with relevant nutrients of life in order to keep themselves burning brightly.

He often encourages colleagues around him that they must have things in life that they once dreamed of doing but have not yet fulfilled. There are many such examples among his medical colleagues that have interests outside of their full-time professions. One such example is how some people work hard to get a barista license because of their love for the strong aroma of coffee. Another example is those people, who are interested in gardening, so they take time to study gardening therapy. Lo Hui-Chung insists that "The key aspect of self-care is to figure out and do something that you like, something that is meaningful to you and can recharge your well-being."

Understanding and Affirmation Release Multiple Pressures

The physical and mental work faced by the wider family caregivers in the hospice care ward can be quite a different environment than in other hospital wards.


Image by jcomp on Freepik

"About 70% of the family caregivers in Taiwan are women, and the first thing they face is gender oppression," according to Lo Hui-Chung. Additionally, he has found that filial piety is like an invisible shackle in many cases, and it is tied to every single family caregiver. He observes, "The family is full of expectations, which can sometimes be unrealistic and unachievable, yet all these expectations are placed on the primary caregiver."

When the patient's condition starts a downward decline or the condition changes suddenly for the worse, both self-blame and blaming others will strike painfully, and the enormous pressure the caregiver bears can be overpowering.

Lo Hui-Chun often looks on helplessly at the clinical scene how the many main family caregivers are often putting the caregiving responsibilities at the forefront, and put their own needs, rights and voices in the background. This sacrifice of oneself for others for extended periods of time eventually leads to emotional distress, relational conflicts, and even physical problems, among which sleep disturbance, headache, neuralgia, and gastroesophageal reflux are the most common. At times, it can also lead to the more severe cases of falling into deep depression.

In this regard, Lo Hui-Chun strongly appeals that the burden of family care should not be placed on the same person, but that everyone should be involved as they coordinate the rotation of caregivers. Even if they really cannot find time to help, they can still find a substitute in order to give the main caregiver a day or two off to recuperate.


Image by Lifestylememory on Freepik

Lo Hui-Chun concludes, "Of course, the family support system must also be sufficient through communication. Using clear and open dialogue, the family members can enhance mutual understanding and support and let the primary caregiver know that he or she does not have to shoulder all the responsibilities alone." He believes that only when every family member can learn to appreciate the intense pressure placed on the main caregiver can they then provide the most appropriate support both in substance and empathy. He suggests, "Sometimes it may be just a simple word, a consideration, a gesture, or an understanding. In many cases, it is enough to provide the necessary support for most primary caregivers."

Long-lasting Palliative Care — Make Good Use of Resources and Ignite Energy for Self-care

Palliative care is an important topic, especially as caregivers are consumed in all aspects of their physical, mental, social and spiritual energy when caring for others. Nevertheless, if they know how to make good use of resources and constantly remind themselves to take care of themselves, they will have enough support throughout the times of their dedication and commitment in palliative care.

Be it the end-of-life care or the long-term care process, palliative care is definitely an extended war of attrition. For family caregivers, patience, will, and emotion may wear away bit by bit in the process of giving care. For professional caregivers, the struggles of burnout, stress, and the burden of life and death also increase over time.

Regarding the various pressures on caregivers, the government and the public have gradually improved the relevant support systems. Through the process of seeing and discovering how and when caregivers face severe challenges in physical, mental, social and spiritual aspects, they hope to reduce the sense of powerlessness as caregivers had experienced before.

Accepting the Responsibility of Palliative Care, including the Physical, Mental, Social, and Spiritual Challenges

"No one is born to be a caregiver," says Guo Ci-An, Chairman of Taiwan Association of Family Caregivers. She pointed out that family caregivers are often caught off guard and hesitate in having to provide care. At the same time, she also notes that everyone is likely to suddenly take the role of the helpless caregiver one day; it seems inevitable.

According to the observations of the Ministry of Health and Welfare's Department of Long-term Care, with the changes in the course of the disease and the degree of dependence of the care recipients, the six dimensions of pressure that family caregivers face will also add up, including: (1) psychological burdens such as fatigue, anxiety, and helplessness; (2) career burdens from the difficulty to balance work and life; (3) social burdens of increasingly distant interpersonal relations; (4) economic burdens such as medical expenses and income issues; and the (5) family burden from the possible disagreements among family members.

In 2007, a survey report published by the Taiwan Association of Family Caregivers (commissioned by the Department of Health) showed that each caregiver devoted an average of 9.9 years and up to 13.6 hours a day. Such a heavy and stressful life made 20% of family caregivers suffer from depression, with another 65% prone to depression, 87% suffering chronic mental fatigue, and a higher mortality rate of 60% than that of non-family caregivers.

This shocking statistic concerned Guo Ci-An. She believes that as Taiwan has entered a low birthrate and super-aging society in recent years, the current situation of the care scenario must be more demanding than it was 12 years ago.

Other than family members, professional helpers on the front line, such as nurses, social workers, and care attendants, also shoulder the heavy burden of care. Even though they have received professional training, they are also under intense pressure and loss in the day-to-day workplace, which can lead to emotional exhaustion. Cai Pei-Zhen, Chairperson of the Department of Social Policy and Social Work at National Chi Nan University, observes that professional caregivers, who have direct and frequent interactions with patients and their families, tend to face exhaustion under such high pressure and great emotional burden for extended periods of time.

With the Support System, One Is No Longer Alone on the Road of Palliative Care

Predicament and despair seem to gleam dimly and unpleasantly in front of caregivers, but they are not left behind in the social care system.

"Taiwan Association of Family Caregivers has entered its 26th year since its establishment. We are the first country in Asia to establish a caring family caregiver organization," Guo Ci-An affirms, noting that Taiwan has listened to the cries of help from caregivers for a long time. In the long-term care plan, the government is also releasing sufficient and diverse care resources for caregivers. Additionally, there is increasing support from the public. The Long-Term Care Services Act, which was established in 2015, explicitly includes family caregivers as its service targets.

Yang Ya-Lan, a special commissioner of the Department of Long-Term Care of the Ministry of Health and Welfare, further explained that for family caregivers, the government provides support services such as fixed-point and home-based care, provision and referral of relevant information, long-term care knowledge and skills training, respite care service, emotional support and the referral of group services, as well as other services that help improve the capacity and quality of life for family caregivers.

On the other hand, according to the estimates of the National Development Council, Taiwan will enter a super-aged society in 2025, and the latest data from the Directorate General of Budget, Accounting, and Statistics also show that there may be more than 13 disabled elderly people out of every 100 elderly people. In the face of this irreversible trend, the deployment of care resources must be rapid and universal. Therefore, in addition to the long-term care 2.0 service, the Department of Long-term Care has also subsidized local governments to establish family caregiver support service centers in their counties and cities. The number of these service centers grew from a mere 29 in 2017 to 114 by 2021.


Image by Lifestylememory on Freepik

"After the passage of the 2015 Act, resources have emerged and gradually improved," says Guo Ci-An, a member of the Long-term Care Promotion Subcommittee of Executive Yuan. He believes that there is still a lot of room for improvement and reinforcement in order to complete the social support resources. Compared to other countries, Taiwan's care for caregivers has already taken the lead. He points out, "There are few countries in the world that can provide so many services. Even European countries with relatively sound welfare systems find it difficult to achieve."

Guo Ci-An is also pleased to say that not only has the government passed laws to promote such services, but also the private organizations have offered relevant courses, provided psychological support, and set up support groups. Guo Ci-An assures, “If caregivers can make good use of these resources, they will be empowered to move on."

Strength Emerges Where Self-care Awareness Increases

For family caregivers or professional helpers, self-care must be the key in order to maintain the energy needed for long-lasting care.

A social worker who has worked in a hospital for 10 years, Cai Pei-Zhen has also experienced the deep exhaustion of these long-term caregivers. She emotionally expresses that caregivers must consciously take care of themselves every day, advising, "If you want to stay on the path of continuous care that is lively, happy, and powerful, the first and foremost objective is to take good care of yourself."

In clinical practice for many years, Cai Pei-Zhen realized that palliative care tests one's sense of responsibility and ability to love. With love as the base, one can be more actively engaged. She observes, "The problem is that those who have burned out are also the people who loved the most. The result of neglecting self-care is that many caregivers suffer from health problems and depression of their own."

With the impact of family structure changes, Cai Pei-Zhen laments that the responsibility of palliative care in most modern families is on just one family member, either because of employment challenges or because the caregiver is sympathetic to other family members. However, with the lengthening of time and changes in the condition of the illness, it is not only likely that the caregiver becomes caught in the predicament of physical and mental exhaustion, but other family members may have difficulty to prepare for the eventual farewell of the patient.

"We have seen in the clinic that when many dying patients finally leave, only the caregiver is psychologically prepared with the departure, while other relatives and friends are not," observes Cai Pei-Zhen. She adds with sincerity, "Getting everyone involved in the caregiving process is conducive for everyone to better deal with separation anxiety and anticipatory grief. Furthermore, it helps reduce future grief related to self-blame for not having participated in the palliative care."

Effective Use of Resources Provides the Necessary Rest for Caregivers

What Cai Pei-Zhen felt is often seen by Guo Ci-An at the service center. A woman who had been taking care of her parents for 30 years told her that during the care process, she collapsed more than once to the point that she wanted to slam her head into a wall and die.

"There are quite a few caregivers like her," states Guo Ci-An, who can’t help but plead with all her heart that rather than be a super caregiver, one needs to make the best use of resources and arrange his or her own time. She urges, "Only if I myself don’t collapse will the one I am taking care of not fall.”

Someone once questioned this, asking "Are you disregarding the values of filial piety by saying this?"

Faced with such a confrontation, Guo Ci-An felt helpless, but remained calm to explain, "With the physical strength renewed by making good use of resources, caregivers can enjoy the simple yet important things in life, such as savoring a cup of tea, watching a movie, and facing life at ease for a few precious moments. Otherwise, when caregivers are constantly busy giving themselves to others, how can they be expected to have the strength to even smile again to the person they are caring for?”

She believes that when the caregivers are immersed in emotional turmoil, they will also drag the care recipients into the valley, saying, "They will feel that they have contributed nothing and are dragging others down. Many patients even feel that it is better to die as soon as possible in order to free everyone else from the burden of caregiving."

Over the years, she has even seen many caregivers who are alone on the road of palliative care. They endure until they are not only exhausted, but also, the relationships with their family become tense. Eventually, they surrender, but the broken relationships within their family are difficult to mend as they face the predicament of loneliness in old age.

Therefore, whether as a family or professional caregiver, only by realizing and being aware of the importance of self-care, and making good use of the support resources provided by the central and local governments, will one be able to walk unwavering and successfully down the road of palliative care.

Heavy Burdens Weigh Down Front Line of Hospice Workers — Professional Intervention Provides a Strong Pillar for Palliative Caregivers

Being on the front line of hospice wards, the nurses bear an unimaginable burden as they face patients who need attentive care, whether due to the intensity or tension of their work. In addition, they are under great pressure due to insufficient manpower in clinical on-site care, low psychological support, and the high expectations and sustenance from patients and their families.

Having been in the internal medical ward for seven years, Ms. Xiu-Mei has seen too many heartbreaking scenes. After numerous patients try their best persevering through various treatment methods, they finally take their last breath in a state that can be too unbearable to look directly at.

Recalls Xiu-Mei, "There was once an old man whose skin was bruised from injections, but before it could recover, a new needle was inserted due to the start of a new treatment." Even though he was a patient she had taken care of more than ten years ago, she still remembers vividly that the blood vessels in the old man’s skin was almost indistinguishable. She winces, "After the new treatment started and a catheter was inserted into his neck, he passed away the next morning."

"If we were unable to save the patient, could we at least make the last leg of his life journey more comfortable?" she wonders. Soon after, the idea of being in the hospice ward came to fruition as Xiu-Mei was transferred to serve in the hospice ward.

"But it was actually very painful after I entered hospice care," Xiu-mei sadly mentions as bitter memories quickly flood her mind. She had once thought that the hospice ward would be the much needed new beginning for her nursing career, but she never expected that everything would be completely beyond her imagination.

Manpower Shortage Brings Unbearable Stress

The first difficulty Xiu-Mei faced was the serious shortage of manpower.

There are many reasons for the shortage of manpower in hospice care. One is that the health insurance payment is not sufficient, which has a negative impact on the operations of the hospital. Therefore, in the allocation of manpower, unless the hospital provides strong support for hospice care, most of it is supported by the most basic staff. Besides, in domestic medical training, rescue and prolonging life are still the main focus, and hospice education has not been paid much attention to. Lastly, the necessity to bear the weight of life heading to nowhere but death is often one of the main reasons for hospice care being ranked last in the career priority list.

In Xiu-Mei's impression, during her three years in the hospice ward, practically every night shift had only one nurse on duty, but this nurse had to take care of nearly 18 patients. She says, "I tried to send more people, but they typically stayed only very briefly. Whenever the hospital is short of manpower, they were usually transferred away.”

Once, among the 18 people she took care of, there were three patients who were prone to hemorrhage. Almost all night, she immersed herself in wiping the pools of blood on the patient's body and on the floor. It was difficult for her to persist until finally the dawn arrived, and she was finally able to finish her shift. Only then did she realize that her uniform was already stained with blood.


Image by Freepik

In addition to being busy, the lack of manpower in the night shift brings unbearable pressure to the nurses on duty.

"One day when the shift was over, I knew that probably four or five patients might be leaving in my shift." That night, her nerves were tense. Unsurprisingly, one patient was dying. At the same time, from a non-hospice ward came the request that one of their patients was in shock and needed urgent CPR. Xiu-Mei immediately woke up the patient's caregiver and asked him to notify the family to come to the hospital, and then hurriedly went to the non-hospice ward to help.

"As a result, when I came back, the patient had already died, but because the caregiver was so tired from already taking care of him for many days, he forgot what I had just told him to do." Fortunately for Xiu-Mei, in the handover document, the family members clearly stated that it wouldn’t matter if they were notified to come to the hospital after the patient died, which provided some small comfort.

When the family members arrived, their emotions were stable, and they also carried out the parting care of the deceased with the assistance of Xiu-Mei. However, due to the disease, they were unable to close the patient's eyes and mouth, and finally had no choice but to let the funeral parlor handle the follow-up cosmetics of the deceased.

"That's how it went,” recalls Xiu-Mei. “As a result, when the family members came for the discharge procedures the next day, they started crying hysterically and berating us for letting their family member not die in peace." Even though it is a memory from many years ago, the phrase "not die in peace" is still like a heavy rock which weighs on her today so that she could hardly breathe sometimes. Such a serious accusation would break her heart to tears in the years to come.

"It was illness that kept the face of the deceased not intact. If a person dies badly, the nurse is to blame, but should I have to sacrifice my life to prevent this matter? Because he was already dead, there was nothing I could do about it," Xiu-Mei reminds herself in an attempt to provide herself lasting comfort.

The Influence of Guidance Boosts Frontline Confidence

The lack of manpower, the emotional state of family members, and unending pressures are placed on the shoulders of the nursing staff in the hospice ward. As a result, day after day, the enthusiasm for hospice care in the hearts of many clinical nurses is eroded little by little.

While some are better prepared than others, in order to avoid lasting emotional injuries, these nurses choose to let their once enthusiastic hearts become indifferent and calloused. However, the formation of this high wall of indifference not only distances them from their patients and their families, but also causes a gap among their colleagues due to differing goals.

Ms. Xiao-Chiao, who devoted herself to hospice care as soon as she graduated, said that she is happy "Because the senior nurses in our unit are very enthusiastic!

If they hadn't been encouraging us and guiding us, I think in the face of the huge pressure of the hospice ward, I would have wanted to quit soon!”

On the site, she saw that many patients were repeatedly admitted to the hospital. Able to speak at first, they gradually became weaker and weaker until even medication could not completely relieve their symptoms. For a long time, whenever a patient passed away, Xiao-Chiao would always reflect, asking herself, "Have I not done enough? If I could do it over again, how would I do it better? "

Facing the patients’ departures during her work hours, the young Xiao-Chiao was not without stress and fear, but fortunately, an experienced senior nurse chose the right time to give her a life-long consolation. Xiao-Chiao shares, "The senior nurse told me that since the patients are willing to leave life during my shift, let me help them clean, change clothes, and walk the last mile of their life, it means that they trust me very much.”

Once, she was struggling with whether she should uphold the professional image that a nurse should have after the death of a patient and hide the sadness in her heart. However, the senior nurse assured her that when nurses were sending off the patients, the sadness and weeping are, in fact, very normal, advising, "After all, you have feelings for them when you take care of them. It's natural that we cry."

Limited Experience Is a Challenge to Overcome with Time

Being able to work in a team that goes all out for hospice care, Xiao-Chiao always regards it as a blessing; however, she has also experienced many setbacks along the way.

Due to the shortage of manpower at the hospice site, most hospitals can only dispatch new nurses to the hospice ward. Lo Hui-Chun, a psychologist who provides counseling at MacKay Memorial Hospital’s Counseling Center, sympathizes with these nurses who devote themselves to hospice care as soon as they graduate. Based on his research, he further analyzes that, in the face of high-intensity work such as hospice care which confronts life and death issues, the average length of years needed to build sufficient psychological strength as caregivers is at least 10 years of relevant clinical experience.

Xiao-Chiao says frankly that when she was 22 years old, the age when she first entered the hospice field, she was like a baby chick that mistakenly wandered into the jungle. She reminisces, “I had thought the patients in the hospice ward would be well prepared to face their death; but in fact, they are still afraid. There are many knots in life that are hard to untangle, and death is one such knot."

She knew at that moment what she had to do was guide and comfort the patients; yet at the same time, she was struggling with these difficult life issues, which were completely unfamiliar to her. She recalls, "Whether it is life or work experience, I had just taken my first steps into society, and didn’t have enough strength to guide my patients. Furthermore, school education did not prepare me much in this respect.”

Faced with such a predicament, she had to be grateful once again for having found strong support, saying, "Fortunately, the senior nurses are very helpful, but we also realized that we had to catch up with them soon."


Image by Freepik

In the challenges of hospice care, most situations are not without solutions. Xiao-Chiao's support comes from the help of the environment. However, in the hospice site, there are many nurses who are not as lucky as her, and they can easily become deeply psychologically burdened, and unable to bear the consequences.

Xiu-Mei, who has transferred to serve in another unit, suggests that if the hospital can provide professional psychological support and pay attention to the lack of manpower in the hospice, perhaps the predicament of hospice care can be broken. She concludes, “Even as professional caregivers, nurses themselves desperately need the care of professional intervention. Please don’t place us, who are on the front line of clinical practice, as a last priority of many improvement projects.”