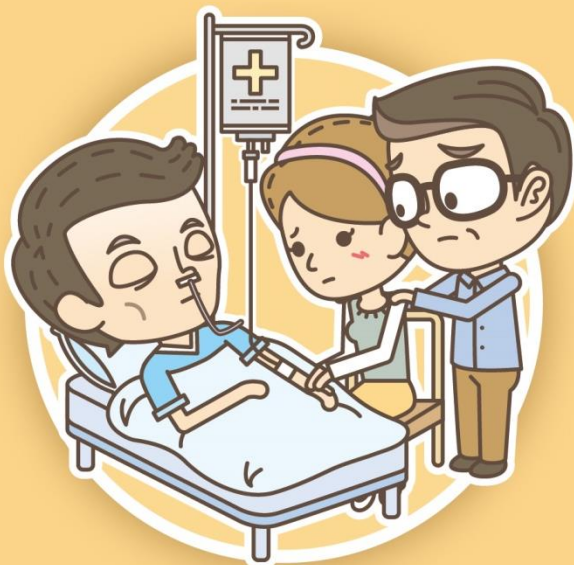




Non-cancer Terminally Ill Patients can Benefit from Palliative Care PART 1

According to statistics, almost 40% of advanced cancer patients are receiving palliative care, but for the non-cancer patients, the percentage drops to merely 0.4%. Based on physicians' analysis, this drop is not only because of the social stereotype to palliative care, but also because the clinical physicians have no common consensus as to what defines end of life ("EOL").



EOL definition is still ambiguous for non-cancer terminally ill patients and leads to low palliative care access rate [MORE](#)

Palliative Care for End-stage Renal Disease Patients - Taiwan Experience [MORE](#)

EOL definition is still ambiguous for non-cancer terminally ill patients and leads to low palliative care access rate



by **HFT secretariat**

The EOL definition is hard to apply to non-cancer diseases

“EOL means someone is about to die,” says Dr. Jyh-gang Hsieh from Hualien Tzu Chi Hospital. Palliative care for advanced cancer patients has been promoted for many years, and it is easier for the general public to accept and understand what it is. However, when defining EOL for non-cancer patients and what can be done for them, it is a big challenge for both medics and family members.

The National Health Insurance Coverage for palliative care includes advanced cancer, motor neuron disease, advanced dementia, chronic obstructive pulmonary disease, heart failure, chronic liver cirrhosis, chronic renal failure, and etc. In reality, however, besides advanced cancer patients, other terminally ill patients seldom receive palliative care. Dr. Ping-jen Chen from Chimei Hospital’s Family Medicine Department points out that 25% of the elderly above 65 years old die because of cancer, and the rest die because of organ failure or hypofunction, including heart/lung failure, dementia, and etc. This suggests that most non-cancer, terminally ill patients had a difficult time at EOL without proper palliative care.

Dr. Ping-jen Chen points out that the trajectories of disease progression are different for non-cancer and advanced cancer patients. In order to determine if cancer patients are curable, oncologists categorize advanced cancer patients according to the stages of cancer. However, the survival period of most non-cancer patients could last anywhere from 6-12 months with much instability, and thus, much more difficult to predict than cancer patients.

Dr. Hung-bin Tsai from the Trauma Medication Department at National Taiwan University Hospital acknowledges that current EOL definition is mostly defined by time. For example, EOL for cancer is generally 3 months, but in the United States, it could mean up to six months under natural conditions, and in Britain, it could mean up to a year. Thus, time should not be the only factor considered, but the quality of life should also be a major consideration.



Similar demands when at EOL

Dr. Ping-jen Chen thinks there are two EOL concepts. One is the end stage of the disease itself, and the other is the end stage of life. Currently the definition of EOL focuses only on the end stage of diseases. Hence, for advanced cancer it is clearly identified as having a 3-month survival period. However, non-cancer patients have different progressions of diseases; for example, patients with organ failure might have anywhere from 2-5 years of life remaining and patients with dementia might have up to 8-9 years. Thus, it can be very difficult for clinical physicians to estimate the EOL stage of non-cancer diseases.

The demands of palliative care for both cancer and non-cancer patients have little difference. For instance, breathing difficulties, including breathlessness or pain, are common to both cancer and non-cancer patients. Dr. Ping-jen Chen believes, especially as relates to chronic organ failure for many non-cancer patients, that depression, stress, and emotional pressure are common when facing the irreversible aging process. Thus, these challenges will require the support within family, and also the holistic care from palliative care.

Learn the demand and the right timing

As Dr. Hung-bin Tsai points out, the current difficulty for non-cancer patients when promoting palliative care is the reliance on scientific monitors to evaluate if patients have reached end of life stage, without attention to patients' social backgrounds like values, life experiences, and family. According to a survey conducted by CommonWealth Magazine, more than 70% Taiwanese wish to die well without the means of endo tubes, respirators, or electric shock. Only 50% are willing to accept the fact that their family members are dying and foregoing the mentioned medical measures. According to the survey, unless patients have previously decided on an advance directive, their family members are often caught between filial piety and emotions, and tend to make decisions against the patients' will.

Hence, confirming a patient's personal will is the first step for palliative care. Most hospitals now take a more proactive stance to ensure that non-cancer patients have the opportunity and access to receive palliative care. For example, Chimei Hospital's administration encourages Advance Care Planning, so that patients can plan ahead for necessary medical treatments as well as to receive

palliative care. Additionally, in order to provide palliative care access for non-cancer patients, the palliative team has actively invited all divisions in the hospital to be involved and assist the non-cancer terminal patients with better symptom control. So far this has received positive feedback from the patients and their families, and has ensured better interaction for both sides. This not only demonstrates the value of palliative care, but also increases the percentage of patients receiving palliative care from 6.5% to 25% during the 2011-2015 periods.

So when is it the appropriate time for non-cancer patients to receive palliative care? Dr. Tsai believes that apart from the patients' own will, indicators include comorbidity, frequent hospitalizations, deteriorating physical stamina, and low quality of life. Having extensive experience meeting with patients' families, Dr. Tsai always encourages patients to think about their end stage of life regarding EOL medical treatment.

[<<PREV](#)

[HOME](#)

[NEXT>>](#)



Palliative Care for End-stage Renal Disease Patients - Taiwan Experience

By **Dr. Tsai, Hung-bin**

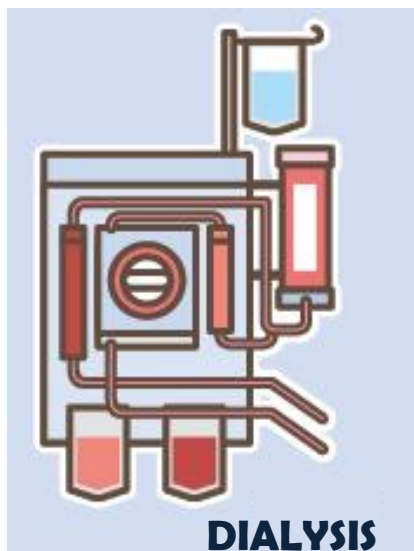
In December 2016, I was invited to attend the Korean Society for Hospice and Palliative Care (KSHPC) winter conference in Seoul, Korea, and shared about Taiwan's policy, research and experience of renal diseases' supportive care. In January 2016, the Korean government passed the Hospice Palliative Care Law and started implementing 2017. The hospice palliative care originally for advanced cancer patients only is now extended to non-advanced cancer patients, starting with heart failure and HIV patients. As for hospice and palliative care for the end-stage renal disease patients, it is still in its pioneering stage.

In order to ensure the right of the terminally-ill patients to die well, National Health Insurance (NHI) in Taiwan has expanded the coverage for palliative care from only cancer and motor neuron disease to include other illnesses such as dementia, other brain alteration, heart failure, chronic obstructive pulmonary disease, lung diseases, chronic renal disease, liver cirrhosis, and acute renal failure.

The purpose of my visit this time is to share about the renal supportive care consensus in Taiwan with the Korean participants. Many expressed their curiosity on how Taiwanese doctors communicate with patients and families regarding the removal of life-sustaining treatment, and why and how a nephrologist works with the palliative team. For example, the dialysis treatment in Taiwan is known for its quality, so why not choose dialysis treatment instead of renal supportive care?

From the standpoint of a nephrologist, if dialysis treatment is the best option, it is without doubt that I provide dialysis treatment of the best quality until the end stage even though the course of disease might be unstable. However, from a palliative doctor's point of view, if a renal disease patient with either advanced cancer receives long term dialysis treatment—which causes vital organ failure and needs to depend on respiratory and 24 hour care in bed—or with serious infection that leads to inevitable death; two specialist physicians can evaluate if the patient has reached the end of life stage, and whether to focus on the quality of life or the quantity.

Taiwan is still facing a difficult bottleneck at the palliative care development of non-cancer patients. Take renal supportive care, for example, where many cannot face the fact that life is about to end. Out of filial piety, children are reluctant to talk about death with their parents, and hence, have no idea how to



DIALYSIS

assist their parents to end their lives with no regrets. Besides, physicians are playing an important role as well. Though nephrologists have all received complete dialysis education and training, when facing end-stage renal disease patients, it is still hard for them to tell the ugly truth. What ugly truth? The truth that once you have decided to go for dialysis treatment, there will be pros as well as cons. If unfortunate, it is very likely that one's lifespan will be shortened; and even if everything goes smoothly, patients might still not being able to meet the ideal quality of life.



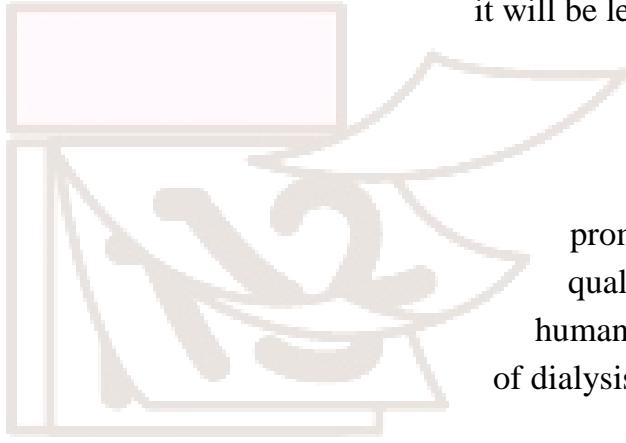
Taiwan Society of Nephrology conducted a survey to all 367 nephrologists in Taiwan last year. One of the questions asked was: “How long do you think a terminally-ill patient will last?” Of the total, 42.8% said within six months, 33% said within three months and 12.8% said within a month.

The survey shows the different perspectives we have when compared with western medics. During my visit to Cicely Saunders Center for Palliative Care, I discovered that the ideal end of life stage for them should be at least a year, so that one can have enough time to prepare for it. They highly respect patients' needs and are totally patient-centered. On the contrary, evaluating the remaining life expectancy is not a high priority. This is a huge difference compared to the US system which often relies on many scientific instruments to predict the remaining life expectancy.

Britain also has a very thorough palliative care system. For patients over seventy with serious renal diseases seeking medical advices from National Health Service, family practitioners are first introduced to patients to provide a detailed analysis on dialysis treatment, so that patients and physicians can both decide whether dialysis is the best option or if there is any supportive care to choose from. Whereas in Taiwan, doctors rarely provide detailed information on the possible complications that come with dialysis, and patients' wills are often neglected and dominated by family members.

Foreign research shows that dialysis treatment can only support fragile elders with multiple diseases for only a one to two year lifespan, that is, two years for those in their eighties, and one year for those in their nineties. However, even though their lifespan is extended, the life quality is generally unsatisfactory. According to statistics, there is a total of seventy-five thousand patients undergoing dialysis treatment in Taiwan, and many patients die while still on dialysis treatment. This made me wonder, is dialysis really the best option for dying well?

When Renal Supportive Care was first introduced in Taiwan, it was hindered by many difficulties and challenges. As consensus has grown during the past two years, family meetings are often being called when long-term mechanically-ventilated patients with multiple diseases require dialysis treatment. Through the Shared Decision Making (SDM) mechanism, the advantages and disadvantages of dialysis treatment will help inform both patient and family members so as to



achieve a common decision. As the complete care planning progresses, it will be less misunderstood and less likely to associate dialysis treatment as a sign of abandonment and hopelessness.

Taiwan Society of Nephrology is actively promoting the ideal of SDM, that besides improving the quality of renal disease care, it is also providing a more humane option for patients to choose palliative care instead of dialysis treatment.

From the perspective of integrated care provided for end-stage renal disease patients, palliative shared care is a feasible and ideal option backed by government policy. So who is the decision maker in palliative shared care, a nephrologist or a palliative physician? At National Taiwan University Hospital, patients are first evaluated by a nephrologist and then consulted by a palliative physician when needed. Being a nephrologist and also a palliative physician myself, I receive many referral patients from other nephrologists, and I believe if palliative shared care can be introduced in SDM, patients' rights and autonomy can be respected and prevent conflict for the families.

I can still recall the instance with an elderly woman in her nineties, who had multiple chronic diseases. Every time she received dialysis treatment, she always groaned in pain. Her blood pressure was not stable and she seemed drowsy. When the treatment was completed, she seemed even weaker than before the dialysis. In fact, she even told the medics that since she was already in her nineties and had no regrets in life, she had had enough of this treatment; however, she continued doing it for her children.

Having less or stopping dialysis treatment does not mean to refuse all medical treatments, but to resort to palliative care in order to reduce patients' discomfort (like edema, asthma, pain, restless and seizures) by reducing the IV amount or prescribing medications. According to the suggestions of Renal Physician Association (RPA), when patients show the following symptoms, there should be consideration to terminate or discontinue dialysis treatment and provide palliative care instead:

- **Patient unable to cooperate: e.g. advanced dementia patients might pull the dialysis needle causing the failure of dialysis treatment.**
- **Patient is unstable when on dialysis: e.g. severe low blood pressure.**
- **Other reasons causing life to enter end-stage: e.g. advanced cancer, dementia or other diseases.**
- **Patients above the age of 75 with chronic renal diseases at stage 5 with poor prognosis, and with two of the criteria below:**

1. Surprise Question: e.g. not surprise if patients passed away after 6-12 months
2. High clinical comorbidity
3. Obvious malfunction in daily life: e.g. Karnofsky Performance scale < 40
4. Severe chronic malnutrition: e.g. albumin < 2.5 g/dL

Taiwan Society of Nephrology has also proposed the following preliminary reference indicator: For patients on respiratory dialysis for more than 3 months (respiratory dependence) and coma scale < 8, physicians and family members should have comprehensive communication to consider the possibility of renal supportive care or limited-care dialysis and avoid the necessary treatment.



Post script:

- There are about six thousand patients on respiratory dialysis each year, and they have slim chances to recover. On average, they survive less than a year.
- Coma Scale: 15 for normal people, < 8 for severe coma and unconsciousness.

[<<PREV](#)

[HOME](#)

