Experience of palliative ambulant care

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Abstract : General practitioner and village psychologist he works in palliative ambulant care. He sees four main functions in the scope of accompanying the dying :

- To help face mortality
- To help elderly people, he has known sometimes for a long time, or younger ones he has just met
- End of life assistance
- To help and support relatives during the last phases of life and the mourning period.

According to him, the purpose of the accompaniment is to make sure the person is reconciled with his or her life so that he or she is able to die without suffering. While for the family it is a matter of being at peace with the loss of a loved one, put it behind and carry on with life.

Description of my job and my working conditions

I work in my small home village. My father was a doctor and I had left during 18 years then returned to become a general practitioner and a psychologist. In this village most people are rather withdrawn, they do not talk much, are Protestants and have little contact with the church. They are rather suspicious towards institutional religion. They all know I practice zazen and I talk about it a lot. Many of them come to see me to find out how to practice zazen.

Attitude towards death has changed

When I was a child, death was present everywhere in the village. People would die in their homes; their bodies were exposed and then taken to the cemetery. The elderly who had experienced war and deportation told us about the death of their own children and grandchildren killed during the war. They would often offer us biscuits destined to their deceased children.

Not so long ago I had a similar experience. I was taking care of a 90-year-old woman who had lost track of her daughter when she fled Russia and had never found out if that daughter survived. Our village welcomes children from Chernobyl during the holidays. This woman had knitted and sewed clothes for these children with the idea that her own grandchildren could be amongst them.

In the old days with religion nothing was brought into question.

Disasters were experienced as a punishment from God, perdition. My father told me he had a female patient once who was very religious and very sick. He asked the priest to come and see

her, and the priest did nothing but tell her: "you are going to die soon, you have to repent yourself!" She was so frightened she jumped out of the window! My father never asked for the priest's help again!

In the 60's-70's, while I was a trainee in a hospital I realised death was disturbing. People would die without being informed of their state of health. At the end of life dying patients were placed in "room 13". A person was left alone and the relatives were not permitted to be present. Sometimes a family member would come and see if he or she was still alive. The family was contacted only after the person's death.

With the development of intensive medicine it was attempted to prevent death.

As a reaction, hospice care emerged in the 80's: how to alleviate the patient's suffering and that of his family during the last phases of life? Hospice care units were created, in hospitals and as ambulant services where doctors and caregivers work together and are specially trained to help people in the last phases of life. I also followed that course and I work in the ambulant service.

My practice

I either have my own patients whom I have known for a long time, sometimes 30 years, or colleagues call and ask me to take care of their patients who have come to the end of their lives.

But death is distressing and the anxiety and the fear of dying take up a great part of my practice. Each examination brings along the fear of a negative result. People do not talk of such fears and I have to pay attention to the words I use. If a patient says: "It's my third cold", I wonder if it is not the symptom of some deficiency in his immune system and that I have to consider and tell the patient by being at the same time, extra careful to the words I use.

I have 4 duties:

- To help face mortality
- To help elderly people I have known sometimes for a long time, or younger ones I have just met
- End of life assistance
- To help and support relatives during the last phases of life and the grieving period.

To help face mortality

Regarding my first responsibility, it is a matter of helping patients face their mortality. Often there are youngsters who are diagnosed with an illness that reduces their life expectation, not only cancer but also cardiac problems or genetic diseases since birth. In those cases patients tend to turn to life without relying particularly on spirituality.

In this group there are also people who are afraid of being seriously ill. They are always afraid of death without being ill. They fear of being subject to God's punishment. Often they blame themselves for something. For instance, I had a patient, very religious or at least who lived very religiously. He was divorced, had a child and had fallen in love again and started a new life. But in his guilty conscience he believed that "God will punish your sins and this punishment will be cursed onto your children up to the 7th generation!" He said he was ready to endure the punishment but asked for his children to be spared. I had no answers to that and I turned our priest. The priest, a clever man luckily, answered him quoting this phrase from the Bible: "God does good to those he loves up to the thousandth descendant."

Some years later, his heart stopped and he had to be revived. He had a near death experience, very strong and suffered from a brain handicap due to lack of oxygen. Today he is all clear and in good physical condition, even better than before.

To help the elderly in the last phases of life

In this second group there are mainly elderly people I have known for a long time. I always have to watch the words I use and what I express indirectly. Many carry a feeling of guilt. An article I read recently depicted the life of a Dutchman who had moved to Canada at the age of 50. Two days before leaving for Canada by boat, he received a fine he had never paid. Just before dying, he asked his son to go and pay it off. His son went off to Holland to do so … but the fine had expired!

Often people feel guilty. I experienced it with my grandmother whose house burned down during the war. She had picked up a box somewhere that did not contain anything special and asked me to find its owners to return it to them, and it made her really miserable.

Certain patients give things away and tidy up their belongings. One woman, who was interested in zen, had 2 Japanese bamboo paintings in her corridor. She told me to take them and said: "These are yours now". It was a sign that she knew she was going to die even if she was not feeling worst than before. During that phase, many people come to see me because they are worried by small physical discomforts or their blood pressure being unstable. To me this is the sign they are facing death.

Another example, one night a man asks me to go and see his mother who was not well. I went and asked "are you unwell?" She seemed well enough, I examined her and everything was fine. Then I wondered why she had woken everybody up. I asked her how it started and she told me she had woken up feeling cold down her back. I asked her if she was afraid it was the cold breath of death. She answered: "yes, I'm afraid of death". So we talked and things got better.

During that period issues of heritage and will also come up. People ask me to confirm, sign officially papers related to a will. At that stage people seek for spiritual guidance, even those who left the church or developed their own ideas. Some even come to practice zazen with me and ask for my opinion.

End of life assistance

At the medical level it is mostly a question of checking the symptoms, treat the distress, the insomnias, the nauseas… Attitude towards death is more singular because it is harder to predict

things than in common cases with illnesses, which require medical treatment. A woman died recently who had insomnias, she was distressed at night and wanted to take some pills I had given her. But only half of the prescribed dose would already cause hallucinations.

Another patient also had hallucinations with scenes of hell where devils would torment her. She was very religious and during that phase of crises, she could not recognise anyone and lived in hell. Her daughters promised they would not take her to hospital. She suffered a great deal and I tried to comfort her with high doses of medicine that would help now and then for one or two hours, but not more. I would go more and more often to give her injections. After 2 weeks, she woke up, recognise everyone, said goodbye, sang carols and died.

Another example: a young man diagnosed with pancreas cancer had already taken a strong dose of morphine he would dose up himself according to his needs. He had gastric intubation and next to it a small stain that cause him a great deal of pain despite the medicine he was taking. I wondered what to do. There was some local anaesthetic gel I used on his skin and it helped him.

These are examples to show the difficulties one comes across. One must attempt everything, think and explore all possibilities in these cases.

Many people have wishes at the end of their lives. A young man diagnosed with a tumour had three last wishes: he wanted to get married and so he did, in hospital. He wanted to see the sea one last time; it was organised and he was given the necessary medicine so he could spend the weekend at the sea. His third wish was to die at home. It was rather difficult because he experienced pain mostly at night and if he was under medication at night he got very tired during the day and could not take part, which he did not like either. He preferred to stay awake all night but then his wife could not sleep and exhausted she ended up saying: “I can’t stand it anymore, maybe it’s best to find a place in a hospice care unit…” I made the Chinese diagnosis using the pulse to estimate the time he had left, and I noticed he was going to die at the latest the next day. I told his wife so she would not feel guilty later for sending him away just before dying. She was grateful (even if her friends found that harsh). He died the next day.

During that period some wish to see a loved one once more. This lady wanted to see her grandson who lived in the US. She waited for him to come and see her and then died a short while afterwards.

This type of help takes a lot of time, I visit patients sometimes once or twice a day. Even if I am away or doing a sesshin, I have my mobile phone to keep in touch.

There is a question regarding people who lose consciousness: what are they still able to perceive? I think that people take in more and more. I experienced that even if one cannot talk to the patient, in the end, the mind becomes clearer and clearer. When my father was on his deathbed, he had a stroke; he did not want to go to hospital and lost consciousness. The day before he died, I was by his side, he was sweating a lot and I was looking for a wet cloth to cover his forehead. He clearly said: “No!” Even though he had not reacted to anything for several days. I thought maybe the water was too cold and so I tried with slightly warmer water. Again he said: “No!”

Another woman patient whose cardiovascular functions were no longer measurable but who was still breathing showed no reaction to anything for two days. I wanted to examine her eyes and took out my lamp. I was sitting on her left and said to her: "I'm going to look at your eye with this lamp". I had not even switch it on that she closed her left eye! She had clearly understood what I had said.

To help families and loved ones

This part always raises the following question: "what does the family want to know?" Do they want to know what the possible complications are, the evolution? Some do not want to know anything and this has to be respected. A common question is: "How long has he or she got left?" In general I do not answer except in certain cases and when it is just before death (like I mentioned earlier). There is also the question: "what can we still do?" Some people find it difficult to say that it is unnecessary to intervene medically, to give treatment. I discuss with them to see what is important and so they feel satisfied with their decision.

Sometimes people find it hard to keep in touch with a dying person. Two daughters were taking care of their mother who had a malignant tumour. During the last phases of life, the mother was in her room on the 1st floor and her son could not go upstairs to see her and would stay on the ground floor. He had already reacted that way when his father was dying. I asked the son if he would come up because he might regret it. And finally when he had reached the doorstep of his mother's bedroom, she died shortly afterwards.

Another example is the one of a man in hospital. His daughter wanted to see him but the family stopped her by fear of psychological repercussions, as she was a little fragile. I talked to the father and the family and advised the daughter to go and see him anyway. The father approved, she went and since became stable psychologically!

After death, helping with the grieving period of the family and the loved ones

Often relatives have the impression the deceased is still around them. Two people told me once they saw the deceased in the room and wondered if they had gone crazy. My mother, after my father's death could not put away his coat and hat. I have often heard that.

There are other phenomena: a friend dreamt that her brother was going to drown in Portugal and the next day he died accidentally. Another friend whose father was on a trip in Brazil, the moment he died, two pictures fell from the wall in her home.

The aim when helping a dying person

The idea is to make sure the person is reconciled with his or her life so that he or she is able to die without suffering. While for the family it is a matter of being at peace with the loss of a loved one, put it behind and carry on with life.

The spiritual element for me is the contact with the patients and the loved ones. This contact is mostly non-verbal; there is a kind of understanding without words.

R.Y.R. I feel there is a big difference between someone who works at the hospital and someone who works in an ambulant care service.

Frauke. I think it is also a question of specialisation. Someone who works in the palliative service of a hospital experiences pretty much the same thing as in ambulant care.

Organ donation… the debate is open

Question. It is a process to die… What do you think of organ donation? I have the impression it interrupts the process of dying?

Response. I also think the process is interrupted and that is what Pim van Lommel, the Dutch cardiologist describes in a fine book(1). In reality we do not know at which stage a person is dead. It is subject to debate; they say a person is dead when there is brain death.
Personally, and each one should decide for themselves, I do not have a donor's card.

R.Y.R. Generosity is the first practice of a bodhisattva and I think that donating an organ for a Buddhist is natural rather than organs being burnt uselessly. It is better to help others stay alive. Of course it interrupts the process of death but medical treatment interrupts the process of death!
What is the use of prolonging life? It is the whole issue of helping. If there is not any spiritual help at the same time, if it is to lead a totally useless life what is the point? On the other hand, to be close to death and to receive an organ may induce the hope that it might provoke a spiritual revolution. A person who lives with someone else's heart, has to feel gratitude surely such act of solidarity changes the mind.
Why don't you want a donor's card?

Response.I do not have a card because I spoke of the cardiologist's book and he is not in favour either!

R.Y.R.What is written in books is not always written by wise men!

Response.My position is not clear regarding that matter…

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(1) Pim VAN LOMMEL, Mort ou pas ? - Les dernières découvertes médicales sur les EMI (Expériences de mort imminente),