
Confronting the announcement of an incurable disease

Mujo, the impermanence and the acceptance of life's limits
when hearing the diagnosis of an incurable illness

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Abstract : Surgeon practising in a hospital. Faced with the announcement of diagnostics of incurable cancers, over time the practice of zazen influenced her in her commitment to the seriously ill, and helped her to position herself in relation to death. She found there the necessary strength to accompany and assist the dying and their close relations, often over a long period.

She denounced the official medicine, for which death is often seen as a failure, instead of accepting this inevitable fact and integrating naturally the end of life in the medical treatment. Fortunately, palliative medicine is developing, trying to relieve suffering and to give the possibility of dying in a dignified manner.

"Once we died at home, with the family and the body was exposed. Now we no longer do that, but I think, she says, we must rediscover this dimension."

As far as I am concerned I have managed the dojo of Cologne for 13 years with Judith and I have practiced zen for 20 years with Roland Yuno Rech.

For 24 years I have worked as a doctor in the department of surgery and from the beginning, I have worked with patients suffering from cancer. Initially I dealt with chemotherapy and the monitoring of psychological and social support for patients after their treatment. Today specialised oncologists handle this aspect.

As a young doctor, I realised I was not only going to be confronted to the recovery and the treatment of patients, but also to the fact of dying and to death. Although such preoccupation had not led my first steps into the profession, the theme of death imposed itself to me. The practice reinforced my consciousness and my wish to be actively involved with it.

After my first year of work I came across the zen way.

The support of spirituality

People come first with a doubt that leads to a diagnosis. In our hospital we treat a lot of patients who have tumours. As a doctor it is one of my duties to inform the patients about their illness and the results of the diagnosis.

There are different ways of informing patients. In the 60's-70's, there was little dialog with the patients. People were not clearly told what was wrong and were kept in the dark. Today things

have changed. Sometimes people do not like to be told clearly, they have the impression the diagnosis is given without empathy or emotion, like a cold verdict.

If someone finds out he suffers from an incurable illness, he is facing the limits of his life expectation. Even if death is absolutely natural and part of life, in the same way birth is, most people do not want to think about it and put it into brackets of their every day consciousness. I have noticed very different reactions among the people concerned. Nobody is happy when facing his or her own death, when it has entered one's sight. I can very easily notice if I am with a person who has already thought about death or, on the contrary, someone who refuses to confront it. For me it is simpler if I meet someone who has led a life he or she is happy with and is capable of calmly confronting death. I have noticed that these are often people who have followed a spiritual path, who are grateful for a life fully realised. They are conscious that each moment is important and live with awareness.

I work for a catholic institution. As Roland said, it is good to know about other religions when one is involved in hospice care. Officially in Germany, I am not allowed to talk about my own spiritual practice of zen. It is stipulated by writing and so I am forced to address spirituality at large. I think it is a shame when I see Rita, in Italy, who has set up a project in a hospital to initiate both patients suffering from cancer and caregivers to the practice of zazen, I find it a great initiative. But in Germany it is not possible. Without naming it directly, I can invite the patient to focus on his breathing. I keep the conversations at a general level without mentioning any specific beliefs, but I still give it a spiritual touch. It is important to me to ask the patients whether they follow a spiritual path of any kind. We give them the opportunity to talk to a priest or anyone else, according to their pathway. But often patients feel the need to talk about themselves and that takes place naturally.

For me it is easier now to help someone to confront death. I can comfort him, hold his hand and simply listen. Without mentioning directly our Way, I give support when someone expresses fear and asks: "What happens after death?" I can talk about my own perspective and how I have accepted that life and death are not separate and that no one can avoid it.

If you say "naturally" in a hospital today there is no time. And it's not natural nowadays to have no time in a hospital. When a patient starts talking, one should take time to be there and listen.

It is mostly at the end of the day when the routine is over, sometimes I tell a patient I will come back at the end of the day and take time to talk. Now everything is very institutionalised and I try as much as possible to answer questions. I often do it in the morning when the head doctor arrives and then I return later to talk more calmly.

If we put ourselves in the shoes of a person who receives the diagnosis and who's life is about to change completely, no one would like to be treated in haste and left alone with the news. With my practice of zen I cannot imagine treating patients that way. If we do not take an interest in the subject of death, we are not ready and we find it difficult to address the questions of the patients and care for them. We need to put ourselves in their shoes and spend time with them.

It is important to understand the other person's spiritual approach.

The materialists, the atheists or non-believers, the people who have had no access to spirituality in their lives, often take a position of denial. I find it more difficult with them because they would not open up and be cared for, but we also have to accept that.

Death “failure” vs mujo

In official medicine, death is often perceived as a failure instead of an unavoidable part of life and hospice care, a natural part of medical treatment. Bernard Lown⁽¹⁾, a great American cardiologist, brought important contribution to the development of official medicine. He condemned the growth of scientific research and technology at the expense of medicine's human dimension. He said: “The death of a patient is not a failure (nor a victory), death is part of life, it's last part.”

In medicine we witness more and more the development of a panel of techniques where, finally, the patient is prevented from dying. The natural process of ageing and dying is interrupted and people end their lives with the support of machines, which I find very inhuman.

With the understanding of mujo, which we develop in the practice of zazen, we realise we are never separate from the dying person because we are also confronted to our own death and to the possibility of dying at each moment.

An essential aspect is to tell the truth to the patient regarding his diagnosis, his prognosis, but it has to be done in such a way that the person does not lose hope. It is best to prepare him or her regarding what to expect, the possibility of treatment, and the repercussions on his family, friends and colleagues. Questions regarding family, work, must be answered, whether it is possible to carry on working for example. We must try to motivate the patient positively without telling lies.

Often the question of the meaning of life comes up

Studies have revealed that life expectation is prolonged by three months when the dimension of meaning at the end of life is addressed. A period of three months may seem short, but it can be of importance to someone who is dying, allowing him or her to put things into perspective and sort out relationship issues. A dying person can be very kind, helpful and willing to sort things out formally.

“From the medical point of view, it is important to understand that in the last phase of life, “to recover” refers here to a suffering human being, and that it may mean caring for an untreatable patient until death.”

B. Lown

While taking care of a patient and particularly of a dying patient, it is extremely important to listen, talk to and comfort him, and give the feeling someone is there to help the best they can.

Palliative medicine

Palliative medicine is developing and its aim is to release the pain and give a possibility to die with dignity.

Question. You said it is important to listen and comfort. I can imagine listening, but how can we comfort someone, what kind of comforting?

Response. First we must listen to the patient's questions and anxieties. We cannot release all the suffering even with the best treatments we cannot stop the pain. At the end of life, people sometimes are very seriously ill and medicine cannot help. It is important then not to leave them alone and to be there until the end. So comforting at the end of life is mostly being present.

Unfortunately, to be allowed to listen is more and more difficult in a hospital, due to the lack of time. However it is important to get to know a patient in order to look for solutions and possibilities to help him.

In palliative medicine we try to improve the quality of life and reduce the patient's pain as well as that of his relatives. The approach is not reduced to a scientific issue and in addition to the state of health; we also deal with the psychological, social and spiritual aspects of things.

It is a bit like the opposite pole of euthanasia. When I talk to a patient and say: "Your life is very limited, you are seriously ill." Often I am asked: "How long have I got left?" Once I got it totally wrong and since then I do not answer that question. Anyway, in general it is difficult to predict. Sometimes people ask me: "I can't go on, can you do something? Could you end it?" With our practice I have adopted the position of not doing it. On the one hand I do not want to maintain life artificially with a machine, infinitely, it is not right and at one moment or another, we must think and stop the machines. But on the other hand, actively helping someone to die is not my thing. If I am asked, I respect it, there are possibilities but one has to find them elsewhere. In Germany it is prohibited, but it is allowed in Belgium, Holland and Switzerland.

In my experience, when we talk to people and offer the possibility of palliative medicine, of hospice care, it often makes the idea of euthanasia disappear and changes the perspectives.

The most important in hospice care are the patient's wish and wellbeing. Each caregiver has his own ideas, his own spiritual way and his own position in relation to death and what comes afterwards. It is important to respect the person who is about to die, to consider him or her as a person and not impose or put through our own ideas. I can refuse to euthanize someone but if that person really wants it, I respect that and I make no judgement.

It is important to respect the wish of the person who is dying, even if we, or members of the family have different ideas or expectations. To be simply present shows that we are ready to let him go if he or she wishes to.

It is very difficult for loved ones and relatives. Perhaps that is when we can support them by looking for external help. There is a possibility with Tibetan Buddhism to do a ceremony, like we do the kito, and hold peoples' hand, pray calmly with them without mentioning beliefs or divinities of any kind.

I am a doctor who works for the official medicine and I find it sometimes terrifying how formal and technical medicine is nowadays, and how little time is given to patients when what is needed is attention and affection. There are specialised medical services, which deal with that, but there are specialisations only. I can ask a specialist to intervene, sometimes I ask a

psychologist. But I think it is important to remember we are dealing with people who are suffering.

When someone has an incurable illness and is going to die within 6 months, there are people who say it is best not to tell them in order to keep hope and energy. Others say it is best to tell so the patient can confront his illness and get prepared. While before I use agree with the first opinion, today I find it important to tell so people have the opportunity to say farewell. It is very important they have that opportunity.

I said it is important to tell the truth with empathy. Regarding time expectation, I was wrong twice, even if my feeling is often right, others have lived for a longer or a shorter period. Alongside official medicine there are natural medical treatments, with "spontaneous" recoveries sometimes, but I do not want to tackle that. Regarding your question I think it is best to be honest.

Sometimes the relatives do not want the patient to be told: "Don't tell my father". But for me the patient is the main focus and it is important to keep his trust, even if the relatives prefer to hide the truth. If the children do not want to talk and tell the truth to their parents, I suggest they face reality and invite them to communicate. Sometimes to protect the family, to settle a will for instance, the patient needs the opportunity to do something. A realistic prognostic has to be made and what the patient makes of it is his problem.

I have an example: my father who had cancer lived for 2 ½ years instead of the announced 6 months. He was feeling good enough. In my family we have lived all this time thinking he was going to die soon, and 2 years later he was rather well. One can see it as a gift, but for my mother it was terrible.

I got my prognosis I was going to die, I have passed it without resistance, I do not resist. My children and I know it. But every day I feel it, and I hope you too, like a gift. At first it was a choc to find myself confronted with the perspective of a limited life. Now the choc has passed and each day is like a gift. And I perceive more intensely what in zen is meant by living one moment after the other. I am a person who wants to know to be able to get organised and take my dispositions, and if there is more time, it is good it is great.

... Anyway, we all have that prognosis!

(1) Bernard Lown, The Lost Art of Healing, Practising compassion in medicine, (Houghton Mifflin, 1996), ou en français : « L'art perdu de guérir »