

## International Perspectives

To launch this first issue of *Innovations in End-of-Life Care*, we interviewed four of our international editors and one additional international physician-ethicist about the broad themes of communication, truth-telling and advance care planning. To ground their discussion, some commentators also spoke about the ways in which palliative care is delivered in their countries. We asked each specifically about the use of advance directives -- living wills and health care proxies -- in their own settings, as well as for a more general sense of how they approach end-of-life decision making. As a group, the commentators focus on the central role of communication in establishing and sustaining effective patient-physician relationships. Cultivating such relationships is key to providing exemplary end-of-life care.

These perspectives are edited excerpts of our conversations and therefore colloquial in style.

*To read about each author, click on the person's name; to read each author's perspective on these issues, click on the country name.*

[Shimon Glick, MD](#)

[Israel](#)

[Linda Kristjanson, PhD](#)

[Australia](#)

[Juan M. Núñez Olarte, MD, PhD](#)

[Spain](#)

[Carla Ripamonti, MD](#)

[Italy](#)

[Zbigniew \(Ben\) Zylicz, MD, PhD](#)

[The Netherlands](#)

### **Shimon Glick, MD**

#### **Israel**

Living wills (specific treatment preference documents) have no legal force in Israel at the moment. There are people that are pushing for them, but thus far they really haven't made much impact. I personally think that such documents are not really the ideal way to go, because it's very hard to predict in advance what the situation is going to be at a given moment. I think designating a proxy, somebody whom you really trust, makes more sense, although we don't have durable power of attorney for health care laws in Israel yet either. We have a patients' rights law, which was enacted in 1996, and the law explicitly outlines what information you have to give a patient. It clearly stipulates that you must tell the diagnosis, prognosis, alternate forms of therapy and side effects. If you decide that the patient would be seriously endangered by telling him something, then you have to go to an ethics committee to get permission to withhold the information, though in practice I don't know of any doctor that has done that.

## **Constraints on Patient Self-Determination**

Also, according to Israeli law, there are occasions when you can give a competent patient treatment he is refusing. This is addressed in the law because, before it was written, the question came up: should you ever force a patient to undergo a life-saving procedure against his will? Before the law was passed, the attorney general called a meeting of about 30 different people, lawyers and philosophers and rabbis and doctors, from all over the country, and he asked, "What should we do?" And on the one side were the civil libertarians, who said, "Of course you can't force anybody against his will, no matter what." And on the other side were some of the rabbis who spoke of the sanctity of human life. One of the philosophers said, "I have a conflict between my mind and my heart. My mind tells me autonomy, but I can't see a guy lying on the railroad tracks, waiting for the train to come, and not push him off even if he says, "No." So the law, as it's written, says as follows: if there's a competent patient, if he's been fully informed, if there's a clear-cut danger to his life, and he could be saved, AND if an ethics committee has reason to believe that if you force him to accept therapy, he will subsequently thank you for it, you can do it. Now, when I heard this, I thought it was ridiculous. You would need skills of prophecy. That was my first reaction. I thought it was ludicrous.

But then, I'll tell you a story. A young Bedouin patient came into the hospital, one of the big hospitals in Israel. His condition was pneumococcal pneumonia, completely treatable. He was having trouble breathing, and they wanted to intubate him. He refused, so the resident did not do it, and he died. That's what you would do in any American hospital. Correct? He was alert, he was competent, and he said, "No. I don't want you to intubate me." So they did not intubate him.

Now this man did not want to die, he was not a cancer patient. He was a young man, he had kids. He was afraid, probably. So, after this case, I saw more sense in the Israeli law. He would certainly thank you a hundred-fold the next morning if he had the tube in for three, four hours and you had pulled him out of this particular phase and the antibiotics had taken hold.

In my ward, we applied this law while treating a hunger striker. We fed him under court order. Most Western countries say it's unethical to do that. The Israeli judge said that in the conflict between the dignity of the patient and his life, in our society, his life must take precedence. But ours is a different society with different values. I think we have a very strong ethos here, supporting the sanctity of life, and still a very strong reaction to the Holocaust.

## **Truth-telling and Paternalism**

There's also a strong paternalistic component to medicine in Israel. Here, the medical establishment basically comes from Europe. Most of the physicians in Israel have not been trained in Israel. So our foundations of medicine are East European, German, Polish, and Russian, all of which are very paternalistic with very little focus on patient decision making. Also, our system in medical schools was the professorial system, where the professor's the head of the department, he makes all the decisions, he knows everything. Students have nothing to say about anything, and patients have nothing to say about anything. We're gradually moving over towards a more Western model, but it's much slower than in the United States. So I think all of those things put together probably make for a more paternalistic attitude towards patients than in America, although it's changing. There's no question that the whole medical scene, as well as the whole society, is changing. But those are the components that really impact on medicine in Israel today.

There was an article in *Lancet* about seven or eight years ago which described what doctors tell patients. They took a poll of gastroenterologists at the European Gastroenterologic meeting, and it was a dramatic demonstration of different cultural views, because those from the Scandinavian countries invariably told the truth, those from Eastern European countries never told the truth, and those from the Mediterranean countries *almost* never told the truth. They gave seven cases and asked people what they would normally do, and as you went further up towards North you went more like the United States model.

Now, I came from the States and lived half of my professional life there, so I am fairly patient-oriented. However, I'm not as great a believer in 100% autonomy as many of my American colleagues are. I've seen many situations where patients defer to the doctor and prefer the doctor to make the decision for them and feel more comfortable that way. While I think one should tell the truth to patients in general, there are times when I don't. And I think there are times when patients don't want it, and they're very upset when you do.

### **The Truth, the Whole Truth, and Nothing But The Truth?**

I think we must treat every patient individually rather than have fixed formulas for everybody. You have to listen to the patient and try to find out what he wants to hear. This is very not easy, and we make mistakes. There was a patient on our ward who had metastatic cancer. This man was not told that he had cancer, okay? He was in a service that didn't tell patients. During a re-occurrence of his disease, he said to the doctor, "Doc, what I had last time I have now, right?" He prodded the doctor, saying, "Why don't you tell me?" Finally, he extracted the information from his doctor. But later, during rounds, he chastised his physician, saying, "Doctor, three days ago, I asked you how things were with me, how much time do I have to live? You told me that things are not good, they're very bad. That's not a way you should talk to your patients." And he proceeded to give us all a little lecture as we went past him on rounds.

I was fascinated by this man and asked him if I could interview him, so we could learn more about the best ways to talk with patients. During the interview, I questioned him, "Why did you ask your doctor to tell you what you had, but when he did, you got angry?"

He said, "It was a stupid question."

"No, no, no," I said. "You're a smart man, why did you ask that question?"

He said, "I'll tell you why. I wanted him to tell me, 'It's not as bad as you think it is, okay? You can survive.' That's what I wanted him to tell me."

So there's the lesson: the patient knows the truth, he wants the truth, but he doesn't want the *whole* truth.

Another patient, a Hungarian woman, was in the advanced stages of cancer. She was still alert, she wasn't going to get therapy, she was in her 80's. She was going to get supportive therapy and palliative therapy and she was quite comfortable and quite happy. She didn't know she had cancer, and her daughter was adamant that we not tell her. What good would I do to that patient in the last week of her life to tell her she had cancer, if her daughter was insisting that that's not what she wants to know?

**Linda Kristjanson, PhD**  
**Australia**

In Australia, a number of the issues around end-of-life decisions, communication, truth-telling, family participation in decisions about the goals of care and advance care planning are addressed in the relationship with the general practitioner (GP), and within the context of the patient receiving palliative care. The GP in Australia is generally more involved in the care experience of patients near the end of life and is more actively integrated into the palliative care service than in the United States. Depending on the region of the country, between 28 percent to 70 percent of people who are eligible for palliative care receive it here, and the GP is very much a part of that system of care. The majority of palliative care happens at home and is provided by an interdisciplinary team and the home hospice service, which is integrated into the general practice program. There is also a roving, consultative palliative care team in a tertiary care hospital and designated beds in some hospitals as well. But the majority of services occur in the community with the involvement of a general practitioner. What's helpful is that the patient and family usually have a long-term relationship with the GP, with a basis for communication.

### **Advance Care Planning in the Australian Context**

Once a person is receiving palliative care, many of the issues involved in end-of-life decisions become almost non-issues. A decision has been made about a type of care, and within that framework of care those decisions are discussed, and in a sense, people accept that certain things won't happen. It is not necessary to fuss about questions such as resuscitation and those kinds of issues. They're taken care of in the move to the palliative care model; it is just part of the ongoing relationship. So that if a patient is accepted into a palliative care service, there's a clear discussion with the family that resuscitation is not a usual practice (of course, that's different if the patient is also receiving supportive care and symptom management in conjunction with active treatment in another setting). Once that's taken care of, the resuscitation matter dissolves, if you will. Questions around other aspects of advanced directives, about tube-feeding or about use of IV or antibiotics, are discussed with the family and the patient as the illness progresses, with the care team trying to stay a little ahead of the family in terms of preparing them and anticipating the kinds of things they may or may not want.

The use of an advanced directive in that setting would be inappropriate because it would be seen, as they say here, as "over the top," which means you wouldn't do it, it wouldn't be appropriate, you know your patients, the relationship is very individualized, this would be seen as a legalistic kind of document that would be incongruent in the context of the relationship. Where it might be more appropriate would be with the younger population who are perhaps healthy, who might be wanting to sort this out with their GP should they develop an illness. And that is not the practice here at all.

### **Truth-telling**

In Australia, the diagnosis is clearly disclosed in the majority of cases. Prognosis is discussed to varying degrees of detail, depending on the relationship with the GP and the patient and the family. I think that when the GP maintains control of the care and care is primarily in the home or in the nursing home setting, there is more openness.

In the acute care setting, it works well when you have a roving palliative care consultative team that's available to anyone in the hospital and can be called in to consult about symptoms, communication

issues, and psychological problems. They seem to act as a catalyst to prompt more truth-telling, more discussion about the actual goals of care, and often facilitate a more appropriate treatment plan; but that depends a lot on the dynamics of the team and the assertiveness of the nurses and other health-care professionals to call this team in. You'd find this kind of very experienced palliative care consultative team in a large teaching hospital in Australia.

Where difficulties with truth-telling occur is if there is a fast downward illness trajectory, and the patient is receiving care usually within an acute-care hospital that is primarily under the control of a specialist, where, the GP may have been marginalized. Then the specialist is steering the plan of care to a greater extent, and will likely have not had a long-term relationship with the patient and family and will be focusing more on active treatment. And the person moves from active treatment to death. The family has not been prepared and no one's really put this together in a very coordinated way. That's where you see the difficulties, when there hasn't been opportunity to discuss things. The specialist involved isn't focusing on that aspect. He or she is focusing on tumor response to the treatment, rather than larger issues, and sometimes this creates problems for the staff.

So there are still a number of problems associated with truth-telling and "breaking bad news" and a lack of training and education among health professionals and doctors in particular about this whole communication issue. We've recently conducted a small Delphi survey of the cancer nurses in the service where I have a consultancy, to identify the key issues related to providing cancer care in an acute care setting. More than half of the concerns relate to communication and palliative care. It comes up again and again, and the nurse feels like--this is a phrase they use-- "piggy in the middle," which comes from a little Australian game. The doctor may not be completely open, the nurse is having to negotiate the day-by-day care and the family's asking questions or the patient's asking questions, and there's a lack of clarity about goals. That's still a difficulty that I think we need to seriously address in terms of education and the comfort of health professionals in being able to talk about this, because even if they know that they should discuss these matters, they don't know how to. There are also difficulties with team communication in sorting out the goal of care.

### **Advance Directives as a Communication Tool**

And that's where a communication tool would be very useful, which is basically what an advance directive is. It's a cue, it's a way to open the door, so I think those kinds of things might be a catalyst to opening up discussions about this in a more open way.

One study is underway right now to examine the use of written advance directives in the nursing home population. In that care setting, when patients and families talk about what they would like in the way of advance directives, 90 percent of them say palliative care. If they become ill, if they become faced with an unacceptable illness, if it debilitates them -- that's the route they would want to take. The challenge of implementing this practice is the cost associated with educating all the care providers who may have to act on this advance directive. The cost in time associated with working through the advance directive with patients and families is seen as quite large. Also, the need to then go out to all the hospitals where the patient might suddenly arrive with one of these on their record and know what to do with it has taken a great deal of money and time.

Some of the families don't think we need to do this degree of serious detailed documentation about advance directives. Others have found it to be quite helpful saying, "We've never talked with Mom about this, and we didn't know how to talk with her about it, and it's been very helpful." The staff

have been quite welcoming of it, once they understand, they think that this is a good idea and think maybe they should get one for themselves. People in their 40's and 50's are more receptive to the idea that this might be useful. Older populations tend to say, "Well, my doctor would know best anyway, wouldn't he?" and so they tend to be more passive in the care-decision process and here are quite trusting. There isn't the history of concern about litigation there that you find in the United States.

### **Culturally Appropriate Communication**

As the number of new Australians increases, with vastly different cultural and religious backgrounds, communication issues about end-of-life care are a challenge for the staff. The country has been predominantly Christian in terms of religious background. As we have more people come to this country of Muslim background, for instance, it's been a challenge to know who to communicate with, who the gatekeepers are in terms of information-sharing, especially with the patient; how information is shared and communicated, gender differences, and the importance of not taking away hope, which can be a limitation in talking candidly about treatment outcomes. And who controls that communication? These are problems.

We have very, very little information about the Aborigine community, for example. Aborigines who present with cancer do so generally at a much later stage of disease. There are some beginning studies looking at beliefs about cancer and palliative care among this group of people. We need to be able to understand these culturally held views. There may be many Aboriginal dialects and languages, for example, in one community. At a conference, Deborah Prior from Queensland University reported that there is no Aboriginal word for "health"; the word that is closest in translation would be "body-spirit-earth." So, the notion of one's own personal health would be a very different concept. The idea of an advance directive to take care of an individual's self-determination needs would be inappropriate. What a person from this cultural background might be more concerned about is the good of the community, and that there's probably something out of balance with body, spirit, and the earth and the community. So the cultural issues about provision of care are really important.

**Juan M. Núñez Olarte, MD, PhD**  
**Spain**

### **Truth-telling**

We've been doing a lot of research on truth-telling, and I would say that the picture nowadays in Spain is complex and fluctuating. Society's changing continuously, and on the one hand, we are no longer the Spaniards we used to be 100 years ago, and on the other hand, we are not just part of the 'global village.' We have to accept that we are simultaneously dealing with different generations and different situations.

What you find, summarizing all these data, is that roughly, presently, something like between 25 to 50 percent of cancer patients in Spain have their diagnosis disclosed to them. But, if you take into account suspicion, or even what we call *subjective certainty*, this percentage would rise to somewhere between 40 to 70 percent of patients knowing the truth about their condition. Subjective certainty is a concept we developed, based on our research and experience with cancer patients in Spain. It means that the patient knows for sure he's going to die, or that he has cancer, but no one has told him. But he knows for sure. He does not need anyone to tell him, because he already knows.

On the other hand, depending on the particular study, somewhere between 16 to 58 percent of patients do not want to have any more information on the true nature of their disease. In our own study, we found that one third of our patients wanted to know and they knew; one third of the patients did not want to know, and they did not know, and one third were halfway between ñ they only wanted a little information. But when you are facing death, if you want a little information, actually, you are saying you do not want information. This third group, then, seems to be a mixture of does-not-want-to-know, but suspecting, the truth.

Relatives are also frequently against truth-telling: depending on the study, somewhere between 61 to 73 percent of the families do not want truth to be disclosed to the patient. Some people describe a 'conspiracy of silence,' wherein relatives prevent patients from obtaining the truth. But perhaps this is because the families know the patient, and they know the patient does not want to know.

There is a similar problem interpreting physicians' behavior. In the initial studies, because of the influence of the Anglo-Saxon approach, there was a tendency to look at these figures of a large number of physicians not wanting to disclose the truth as not being in a good direction. At that time, there were no data coming from studies of patients themselves, and so the early researchers were expecting patients to behave the same as they behave in other environments. With the data we have right now, I think it's that the physicians, in a way, are mirroring the population they are taking care of.

Probably, if a physician is already an experienced physician who has been working for a long time, he has been exposed to a lot of patients, over two or three decades. In his early years, when he was shaping his attitude towards truth disclosure, he was facing a population in Spain that was even more adamant about not knowing. In fact, that's something that came out also very strongly from a study and was statistically significant: the younger the patient is, the more willing he is to have information, whereas older patients don't want truth to be disclosed.

### **'Spanish Death' - Ars Moriendi**

The traditional good death in Spain is what we call "Spanish Death." Spanish Death is the traditional style of death that has been in place in Spain since the 16th, 17th century, and the Counter-Reformation. At that time, Spain was a predominantly Catholic country, strongly supporting Counter-Reformation after the Reformation and the birth of Protestant churches in Northern Europe. It was very important at that time to stress several aspects when Catholic Spaniards were facing death. Those aspects were basically that death was something very good, not bad...you were dying in this life, but you were being born to a much better life, so it was not acceptable that someone would cry or that anyone would react in what we would call nowadays a very human way. At that time, this kind of wailing and crying was not acceptable, but realizing that it was inevitable that a death would have an emotional impact on relatives, the treatises of good dying in Spain stressed the importance of the relatives not being around. These treatises, called "*ars moriendi*," were very popular.

The physician would come into the room, saying that there was nothing else to be done, then he would retire. Then you would have the priest come and help the dying to prepare for the impending death. At that time, relatives would have to go out, and then friends would come in, and these friends would have to be Catholic and pious and they would keep telling the man or the woman that what was going to happen was not bad, but good. We were very, very strongly devoted to this.

Let me point it out this way. If you think about the two kings who have been the most important kings in the history of Spain, they were Charles V of Germany and Spain, and Phillip II. Both lived in the 16th century. Both retired prior to their deaths. Charles V didn't die a king. He asked his son Phillip II to take the kingdom, and he went into a monastery for 7 months to get ready for his death. His son later did the same, and died in his bed in his palace, which was built in the monastery.

Just imagine, in the span of 100 years when Spain was the most important country in Western Europe, the two monarchs gave the same message to the kingdom: You have to get ready. At that time, sudden death, what was called the '*Mors subita et improvisa*,' was really hated. That was the worst death that you could expect, because you were not allowed time enough to get ready for it. So most Spaniards who were literate would carry in their pockets, what were called '*Cartas de Aviso*.' These "warning letters" were small pieces of paper on which were stamped or painted images depicting death or dying or the saints or the Virgin Mary, with admonitions in verses that were reminding you of the fleetness of life.

I'm not saying that patients who are dying in Spain now are dying the way they were dying in the 17th century. No way. But sometimes, you find what we call "Spanish Death" in our elderly patients. We use this term regularly in the unit. When we find one of these patients, and we are discussing in the team how to take care of him, we say, 'oh, Mr. So-and-So is dying Spanish Death.' That implies a very specific approach we have to take with the patient. These patients come from rural areas; they are not very literate. Probably they are re-enacting the type of death they witnessed from their father, who witnessed the grandfather's death, who witnessed the death of the great-grandfather. It probably has nothing to do now with religion. Nothing to do with convictions. It's a cultural pattern.

And then there are some things you have to be very careful about. For these patients, invasive procedures are not acceptable. Just performing a fecal disimpaction might be very stressful. First of all, most of them, have *subjective certainty*. They know for sure they're going to die. They don't need anybody telling them. They know it, and they just want to be left alone. If you're very invasive, either with subcutaneous hydration or fecal disimpaction or any aggressive intervention...I mean, you are missing completely the point.

The other issue is that they don't want the family around. There's nothing special about it. It's just that that's the way they think it has to be done. On the one hand, it's intrusive on their own privacy, because they want to be left alone. And most of the time, they take a fetal position, they face the window, and they give their backs toward the door. It's very simple, the message is that they're receding.

This can be very upsetting to relatives. Most of the time, they don't know why this kind gentleman or kind lady, who has been so kind and gracious for most of his life, in their last days of living just don't want to communicate. And I keep telling them, they just are dying the way they think they should die. It's putting a very stoic face on it.

If you don't explain this to the family, they feel guilty. They feel there's something missing, and that they are being punished because something has been wrong. So, it's very interesting because actually the elderly are dying in a cultural environment that is old like they are. Whereas the younger generations don't understand the behavior, and you have to explain what's going on.

### **Advance Directives Have 'Gone Nowhere' in Spain**

In the early 1990s, when the palliative care movement started, there was very strong support for advance directives by the Catholic Church. The church and a lot of other organizations were supporting advance directives, taking them straight from the American model. But the idea has simply gone nowhere. In our own practice, we are the largest palliative care unit in Spain, we take care of more than 1,000 new patients per year. I haven't seen one single advance directive in eight years.

The American model puts a lot of attention on autonomy, a lot of empowering to the patient, and I think that's the right way to go and that is the way we are going now in Spain. But autonomy is not throwing autonomy on top of people. Autonomy does not mean assaulting them with truth, or assaulting them with informed consent, or assaulting them with advance directives.

And, also, we change styles of living during our lives. We change marriages. We change political sides. We change religious convictions. And we expect when we are facing death, we are not going to change? I mean, I am not at all interested in what people are saying when they are healthy. I want to know what people think when they are facing death. Instead of advance directives, you have to understand what people want now.

It requires that you always be sensitive enough to realize what type of patient you are facing. Either you are facing a traditional style of patient then you have to be a paternalistic physician in a way. They don't want to make decisions. And if you try to push them to make decisions, you put them into anguish, you build a lot of anxiety, both in the patient and in the family, because that's not what they want from you. They want from you to make the decisions for them. You have to realize whether the patient is this type 'A', or, if the patient is type 'C' And type 'C' is a young patient with a different approach, who really wants to be informed and really wants to share all the decision process, and he wants to choose the different therapeutic options, even to the very last. But most of the time, they want to choose when there are cure-oriented treatment options. They don't want to choose so much when the treatment is just palliative. You are not choosing how to live, but how to die. And then you have the patient 'B', which is the patient that does not know, but suspects and is caught in between. And I would say that the vast majority of our patients are patient 'B'. It's neither a question of white nor black, it's gray. Different shades of gray.

There's an artistic part to doing palliative care in Spain. You have to have a lot of skills in order to face the patient, try to probe, to understand how much does he want to know? If he's a patient that doesn't want to be informed, or very little, then you have to figure out what his approach is towards certain treatments without actually telling the truth. This is something that is better witnessed than explained. If you come to our unit, or to any unit in Spain, and you just watch physicians doing that, you would immediately realize that we are talking about this without talking about it. There is a lot of nonverbal communication.

### **Default Position on Resuscitation in Spanish Hospitals**

In most palliative care units, it is understood that if there is a cardiac arrest, there is not going to be any resuscitation attempt. That's understood by all professionals, but there are relatives who don't want to understand that. This is not an easy conversation for any Spanish relative. It's like trying to get permission from a relative to perform an autopsy. It's very seldom we get autopsies in palliative care units in Spain, because most of the relatives feel that's the last straw. You're adding the last straw to the haystack and they don't want to take it. It's the last aggression. Even though the

patient's already dead. But they don't want it.

Relatives are not involved in discussions about resuscitation. It is not a concern of patients, nor of families. They are concerned about whether the patient is going to suffer. They are concerned about whether the patient is going to be lucid or not. But they are not involved in resuscitation discussions.

**Carla Ripamonti, MD**  
**Italy**

In Italy, we don't have advance directives; it is not a concept for us. We also have no Do-Not-Resuscitate orders in our clinical charts. We think it is awkward to ask patients too far in advance about whether they would want to be resuscitated. It would depend, wouldn't it, on the circumstances? Because every patient, even if at the very end of life, is different. A patient with good pain control and good family support is different from a patient whose pain we have been unable to control, or who is suffering from very severe dyspnea or from severe psychological distress. One would not resuscitate a patient with very severe dyspnea, but if you had a patient also in the terminal stages of illness but with a very good quality of life, you might try resuscitation if the patient wants to be resuscitated. It is necessary to consider each patient as an individual.

### **An Individual Approach**

The question is: will the treatment bring a benefit to the patient? In Italy, the doctor has the authority to make that decision and so for this reason the doctor carries a great deal of responsibility. However, certainly at our institution, it is often a collaborative decision in which physicians talk with patients and families. It happens within the relationship between the doctor and the patient.

Here at the National Cancer Institute of Milan, and in particular in our division of palliative care, communication is considered a very important part of the treatment, of the cure and the care. One must spend time with patients to understand their needs. How else could you tell if the pain was a physical pain or a psychological pain? Only by talking with the patient can you decide whether to increase the dose of morphine or provide more psychological support.

We speak continuously with patients and their families. Some patients tell us, for example, "Don't prolong my life." Or, "I need to live one more month because I need to see my son." Patients and families and their doctors talk together about what would be the best thing to do. We have a very personal approach, with different goals for each patient.

### **Truth-telling**

Unfortunately, there is not such good communication and discussion with patients and families throughout Italy. In many parts of the country, you will find that doctors do not communicate the diagnosis of cancer to their patients, and they may not have good communication with the family at all. Sometimes patients are treated with chemotherapy without knowing that it is chemotherapy. It is not possible to say this word, "cancer," because in Italy cancer is associated with great suffering. So it is rather difficult for the doctor to use this word and for the patient to accept it without explaining that there exists the possibility to cure the cancer and to care for the patient throughout his or her illness. Perhaps as we palliative care specialists get better at doing this -- letting families and doctors know that cancer does not have to mean suffering, that it is possible to have pain control, to die among family and friends in comfort, perhaps then the word "cancer" will create fewer problems.

But right now, it is often much more acceptable to speak about death than to speak about cancer. To have a cancer is something terrible, while death is part of one's destiny.

Yet even so, after 15 years of working with cancer patients, I have never said to a patient that "you are dying," unless specifically requested to do so by the patient.

One must use appropriate words.

For example, I say, "The illness is very serious, but we can try to control your pain and other symptoms; I will not leave you alone, and I will do everything to improve the quality of your life, but your illness is very serious."

I think it is important to communicate everything to the patient, but it is important to consider the *way* you communicate. We have some patients who want to know their situation exactly and explicitly, so we speak exactly with them. And we give all our patients the opportunity to ask everything. We try to understand what, and how much, they want to know.

I also think that awareness of prognosis or of impending death differs day by day. You could have a patient who clearly knows her prognosis, but when she feels better she believes that death is not near. One day we are able to accept death; the day after, we are not.

Many families worry that their loved ones will not ever be able to accept the truth. Sometimes a family member will take the physician aside and say, "Please do not give the prognosis to my parent or to my son or my mother. He will commit suicide, if he knows everything, or she will grow despondent." In these cases, we see the family as our patient too, and we must give them support. Our home care program has been very helpful in situations like this. When nurses, doctors and volunteers go into the patient's home, they can see how the family is organized; they can help the family each moment the patient is alive. It is important to support the family and to help the family realize that it is important to say what is happening, but one must do so in a *particular* way.

### **The Patient Arrives at his own Prognosis**

The patient must be the real guide. For example, when I have to tell that the prognosis is not good and that the illness is worsening, I speak with the patient, and I ask him to speak about the illness. Through our conversation, he arrives at his own sense of the prognosis.

For example, I may speak about the sites of the metastases, or the fact that the tumor is increasing. If the patient then says, "So my health is worsening," I concur. I will reply, "Yes, it is worsening." Through our dialogue, he arrives at his own prognosis. And you can see this happening. "Is it time for me to call my son in America?" he may ask. Or, "Is it better that I stop working? Should I ask for financial support?" In this way, the patient arrives at his own prognosis in a way that he can comprehend and accept.

After all, none of us can say exactly what will happen. We had some patients come from the United States and Australia and they had been told that they had only six months to live. They spent the last months of their lives in a terrible state, sure that they would die at any moment. It would have been better to say that we do not know with certainty when this will happen, but that the disease is very, very serious and that there is no more point to continuing the chemotherapy and the radiotherapy. We must continue with palliative medicine, we must continue with our presence, with home care,

with a personal, empathetic involvement, but no more chemotherapy or radiotherapy. So, we speak quite clearly about the need to stop anti-cancer therapy, we are clear about the seriousness of the illness, without literally saying, "You are dying."

**Zbigniew (Ben) Zylicz, MD, PhD**  
**The Netherlands**

In the Netherlands, we are not so focused on advance care planning. People do sign advance directives, but they are not fully "water proof." In other words, doctors are not required to comply with them. I believe that these documents as I have seen them used, are of no value. One of the problems is that patients create and sign living wills, when they are healthy. For us, it is important to find out what the patient wants at the moment when he or she is very ill.

**Limitations to Advance Directives**

Here is an example from my own experience some time ago. I had a patient with septicemia and an infection in his bladder who needed to be resuscitated, but he had an advance directive indicating he did not want to be resuscitated. His family came after the ambulance, saying, "Please do not resuscitate him." I didn't comply with their wishes. I did resuscitate him and then moved him to the ICU. Twenty four hours later, he recovered. When I asked him later about his advance directive which indicated he did not want to be resuscitated, he said, "I never meant it for this kind of situation." Doctors in the Netherlands still have privilege and the autonomy to decide in the moment. The law and public feeling are behind them.

We are not under so much legal pressure here, as in the United States, and there is more public trust. Patients are increasingly able to complain about services they receive, but getting money from malpractice suits is unusual. We like our patients to be able to complain and we try to be open and frank, but we do not resort to the legal system to resolve differences.

For these reasons, I feel that advance directives, especially specific treatment requests, are not so useful.

**Relationships are More Important**

Almost half (46 percent) of Dutch people are dying at home, cared for by their general practitioners. Of the remainder, 17 percent are dying in nursing homes and 37 percent in hospitals where they are cared for by nursing home physicians and specialists, respectively. Before palliative medicine was practiced in the Netherlands, patients with complicated terminal illnesses were nursed in hospitals. However, hospitals have 20 percent fewer beds now as compared to fifteen years ago and many patients are discharged to home or to nursing homes where there is a long waiting list.

For these reasons, much end-of-life care is provided by general practitioners and district nurses. They are the most important part of the health care system for these dying patients and their families. They visit about half of their patients at home, and they see the other half in the office. This family doctor knows the patient's priorities and ways of coping, and can be an important source of information. Older people live in the same communities and have the same doctor for twenty years. Their physicians rely on this long-standing relationship and knowledge. This long-term contact among the patient, the family, the nurse and the doctor - it is one of the strongest points in the Netherlands. The patient knows the doctor, the doctor is well paid and someone who is trusted

by the whole family. You cannot see communication separately from the system.

Of course, one disadvantage of our system is that many general practitioners are working alone, in isolation from other colleagues and specialists. That's why a major part of what our hospice does, in addition to the acute care inpatient unit we run, is to provide advice and support to general practitioners in the community.

Isolation is particularly a problem when it comes to euthanasia. Euthanasia in the Netherlands is decriminalized, but it is not legal. In these situations, very often you have one family and one physician, and they must make the decision alone. The doctor can be very attached to the situation, and maybe could benefit from having the opportunity to talk it over with other colleagues. Or maybe the physician needs more skills in pain and symptom management, or how to deal with depression. Our hospice tries to deal with this problem of isolation, by providing help with pain and symptom management and being available as a back-up to the general practitioner.

### **Innovation in the Dutch Context**

An innovation in this country would be to introduce the perspective of palliative care, so as to have an alternative to offer people who request euthanasia. Often these people are suffering from hopelessness. Palliative medicine would provide an alternate way of dealing with this hopelessness. I believe that good palliative care would change a lot of requests. I'm very liberal in all this, I agree people must be free to decide about life and death, but it is not moral to offer only one choice, and with palliative care, you have more choices.

In our experience 80 percent of our patients who request euthanasia are afraid of something -- afraid of losing dignity, of being damaged -- and their request for euthanasia comes out of fear. When you provide them with a safe environment, then they say three days later, "Doctor this is exactly what I meant." Often, once they feel safe, patients never discuss euthanasia again.

Therefore, we must focus on quality of life. We need to bring attention to the patient's quality of life as early as possible. Half of what we are doing in palliative care is prevention, prevention of loss. You can do many things to the patient, for example, control pain, but cause loss of ability to drive a car. In that case, the patient has no pain but cannot drive a car to visit his or her daughter. In my opinion, you cannot start palliative care soon enough and this will require talking with patients about what losses they are willing to accept and which losses they want to prevent. The patient should set the agenda.

### **Barriers to Palliative Care**

One major barrier to offering best palliative care in the Netherlands is a lack of financing. Enthusiastic doctors, charity money and foundations have been supporting this work, and now palliative care is beginning to be officially recognized, but it is still a long process. In order to try to translate palliative care into mainstream medicine, we need to have financing. Under the Dutch national health system people have 100 percent coverage, including terminal care, but in fact, terminal care is not getting reimbursed. On paper, this insurance includes birth to death, but because of a shortage of resources and of how money and resources are divided, there is an enormous shortage of money. This situation is a little bit immoral, because we as a hospice are providing services that are already supposedly covered by insurance but which we are paying for through other means.

## **Opportunities for Improvement**

Up until now, the approach to cancer treatment has been a curative focus -- treatment, treatment, treatment. As the numbers of aged and frail people increase, we will have increasing numbers of dying patients and their families will ask for better care. In addition, I have noticed a change in physicians' attitudes since my training. Medicine in the Netherlands was dominated by men; it was a masculine world. This is now changing rapidly as we have half and half, men and women in medical school. I see an enormous change as women have a completely different perspective; they attend to the quality of patients' lives. They are not so hard and mindless in their approach to medicine!