A Hiding Place

By Jonathan Imbody [i,ii]

Nestled in a pastoral setting near Arnhem, the white, two-story building that houses the Dutch hospice Rozenheuvel offers no clue of the penetrating human dramas that daily run their course inside.

Dr. Zylicz

Zbigniew Zylicz, MD, Ph.D., a graying, quietly dignified man, leads a visitor up a spiraling wooden staircase to a comfortable sitting room where a fountain gurgles soothingly in the corner. He gently settles into a leather chair for another interview, an increasingly familiar event for this hospice care expert—an exceptional figure in a country that has promoted euthanasia over palliative care.

The Polish-born internal medicine and oncology specialist moved to Holland in 1979 with his Dutch wife and his children. A committed Catholic, Dr. Zylich could not countenance the growing Dutch notion that doctors should be entrusted with the power to end the lives of their patients.

Armed with this conviction of conscience, Dr. Zylich never dreamed that euthanasia had corrupted his profession so deeply that a Dutch hospital would not even protect his patients from medical murder. He recalls the incident that ended the life of one of his elderly patients--and irreversibly changed the direction of his own life and career.

No place to hide

"It was a case in an academic hospital. She was afraid to go to the hospital because she was afraid of euthanasia. She was not *asking* for this; she did not even *want* this. And they promised her that nothing would happen to her.

"I admitted her on the weekend to a bed of another patient who would be coming back Monday morning. I had no other facility for her. She was very ill, and I expected she would die on the weekend. But she improved. With good treatment and pain control, she started to talk and she was not dead."

The woman's improvement proved short-lived--because Dutch doctors had begun to see their mission to be not just healers, but killers as well.

"On Monday morning when I went off from my shift and went home, my colleague came and did something. I don't know exactly what he did, but she died within ten minutes. And the nurses called me at home. They were very upset about this. And I was very upset about this, too."

The Polish doctor with religious convictions could not live with a sanctioned assault on the sanctity of human life.

"I said, 'This kind of medicine, I really [cannot live with].' So I quit my job. From one day to another, I was with five children just on the street, with a big mortgage on a house and all kinds of expenses. From one day to another. This was a horrible moment for me and also for my family. But I was not able to work in this [situation].

"And this was not the only single case. This was the whole system working like this."

Hospice launched

Rather than surrendering to a twisted medical system that robbed patients of their lives, Dr. Zylich instead decided to launch an alternative to state-sponsored suicide.

"It was in my life a very important turning point," he explains. That tragic turning point resulted in one of the few full-care hospices in the Netherlands.

"I had always been interested in the field of palliative medicine," Dr. Zylich recalls. "So it was always my purpose to work in a hospice, to develop this part. During my studies, I had visited Saint Christopher's Hospice in London--one of the first hospices [in the world]. Dame Cicely Saunders ran the hospice. In 1994, we managed to start hospice Rozenheuvel as one of the first hospices in Holland."

Providing full-service care

"Our hospice provides three levels of service; we have three aims. The first aim is patient care."

While the Dutch healthcare system lagged behind the rest of the world in palliative care, the Rozenheuvel hospice proved that euthanasia need not be the end of the road for terminally ill patients. Much more than simply a place to die, the Salvation Army-sponsored hospice provided a complete range of care and services to help patients and their families physically and spiritually cope with the end of life.

Dr. Zylich explains, "There are only a few hospices [in the Netherlands] which are high-care hospices—that is, hospices that can provide every kind of care. There are many hospices in Holland, but they are low-care facilities. Low care means that the patients who are not primarily needing medical care can go to the hospice and get the care from their own general practitioner and nurses and also from volunteers. But if anything should happen to them at the end of their lives—for example, they get a lot of pain—they need to go to another facility, because it's not providing enough care in complex situations.

"High-care hospices like ours can provide every kind of care. We never need to move a patient away to a hospital or somewhere else because we are short of knowledge or short of ideas about how to treat a patient."

Besides offering superior medical care, Rozenheuvel hospice also specializes in providing spiritual care and staff for its patients and families.

“We make a choice of our people working here,” Dr. Zylich notes. They must be convinced Christians to work in this house. They are from all kinds of churches and denominations. It is very essential for all of us to have this same Christian background. We may differ in our beliefs, in our church, but the background is the same. The same background—sanctity of life, a feeling of your [personal] role in this—must be the same. It is very ecumenical.”

The spiritual atmosphere at Rozenheuvel hospice has proven a drawing card for patients regardless of their own religious convictions.

“Two-thirds of people who come here as patients don’t believe in anything,” Dr. Zylich observes. “It’s very funny. We have our pastoral worker here and [non-believing patients] like it very much. Even if they don’t believe in anything and have never been in church their whole lives, and don’t want in the last days of their lives to turn to become Christians, they like very much the spiritual, pastoral care. They value this very much. So that’s a kind of ideal we have, from the Christian background, to provide this to the whole society—not selecting people.”

Dr. Zylich leaves no doubt that hospice ministry is incredibly hard work that requires unblinking commitment to patients. It is not for the faint of heart or for those who expect easy solutions.

“We concentrate on the very complex problems where a multidisciplinary team works on them. Very difficult problems. Sometimes we will have six or seven or ten specialists consulting on the same problem. So it’s frequently very difficult. You need to have a lot of time and energy. But we can do a lot for these people even in these situations.

A reconciliation ministry

"One of the most horrible things we have had, I think three times here in hospice, there are people, daughters who are taking care of their fathers who had committed incest in the past. This is one of the most heavy [issues], for all of us, that is happening. This girl needs to live her whole life with what happened, and the father is parting away. It is very emotional for the whole team.

"It is very difficult to talk with the people about this. You feel it is very important. It is a kind of mystery, what is happening…it is so important to people to have the possibility to [reconcile]. Not all people want to do this; not all people are doing this. Our role is to facilitate it. To control the pain--not to just control the pain, but to control the pain to facilitate this kind of process, to make it possible.

“And that is very important. We are not controlling pain just to cut the pain. The same is when we have a patient very much in pain, if we are able to control part of the pain, we try to mobilize the patient; we try to activate him; we try to help him feel like a human being. To give as much independence as possible, so people can walk to the toilet, the bathroom. So they can do things they want to do without being dependent on other people.

“So the symptom control is not an aim by itself, not the end point. It’s just facilitating a lot of processes that are happening here. And this process we see daily, what’s happening with the people. We observe this—the nurses, our pastoral workers, psychologists and doctors—we all observe this daily. And this is beautiful. This is very, very rewarding.

"But not all people go through this process. Some coping styles are so closed. People don't want to get it. They don't want to open their wounds. They don't want to get through this process. And they are free in doing what they want."

Guilt-burdened wife cannot care for her husband

"Most of our patients are admitted in the critical situations," he relates, citing a recent example.

"Yesterday, a general practitioner called me to see a patient at home. His wife is taking care of him. He has bowel carcinoma. So the patient is suffering more and more pain. [The wife] wanted very much to take care of her husband. But she is burned out after three weeks of this care at home. She is alone; they have no children."

As often happens to family members caring for loved ones at the end of life, the wife came to Rozenheuvel suffering tremendous guilt.

"She had promised him that he would die at home, that she would take care of him," Dr. Zylich says. "But it's not possible, or at least very difficult. So I went yesterday to see this patient. And there is a very big stress there. He wants to die at home; he doesn't want to come to a hospice. She wants to take care of him, but she cannot. And he still has several weeks to live."

While many physicians treat only the physical pain, Dr. Zylich and Rozenheuvel hospice go deeper.

In the case of the cancer patient whose wife felt she could no longer care for him, Dr. Zylich explains, "The pain the patient is feeling has a lot of dimensions. A dimension of failure, of promises which were not kept, of the physician not coming when he was asked to—all these kinds of things. The problem is that he didn't want to go to hospice. He is now forced to."

Such cases call for Solomonic wisdom. Dr. Zylich seems to have tapped into that wisdom, and he found a compassionate solution for the desperate couple.

"We admitted both of them to the hospice, so she can keep caring for him like at home. She doesn't need to do this on her own; we will fill the gap. But she will be the most important person caring for him. She will sleep here and maybe later she'll go home for a night if she wants. She has the freedom to do this—to keep just a part of her promise. The other promise is to make hospice like her home, to make it more similar, so that he will feel safe here, as if it is his place."

Integrating faith and healthcare

"I am looking for the way to translate my religious convictions to address people who are not believing. That's my problem.

"It's very easy to make a hospice like this and to say, 'We are not doing euthanasia. This is only for Christians; we do this for our own church, our own closed group of people. We will never have problems, and we can say to all the world, 'See—we don't need euthanasia.'

“But that’s not true. I mean, we invite people here in this house. Being a Christian house, we invite people who want euthanasia. We offer them good care. But we also offer the possibility to go out if they … want to proceed with euthanasia. And it has happened twice in six years in all the patients we’ve had, that someone left the hospice here for euthanasia somewhere else. But with the majority—the great majority--of patients, it happens that we can either convince them, or provide without convincing them, to convince them with our deeds, not with our words.

“In total, there are about 120 patients dying here annually. So it would be about [720] patients who died in this house until now. And a quarter of them are requesting euthanasia when they come here.

“I tell them that we do not provide it, but that what we do provide is good care. They have their own choice to make if they want this or do not want this. But they will always be free to go away from here. And most people understand this perfectly. Because most of the people who are requesting euthanasia—at least in our setting—these people are afraid of something. They are afraid of losing their dignity. They are afraid of being nobody. They are afraid of dying socially before they will die physically. They are afraid of many things which never happen. They are feeling not safe in their environment.

“And this is what hospice is all about. We provide safety; we provide rest for these people. We provide good care.

“But we will not ‘work on them’ while here just to convince them that euthanasia will not be necessary. Not just by convincing them, but by providing good care.

"Pain in your soul"

"I am Catholic and convinced about what I am doing. It plays an important role in all my work."

“We believe in free choice. This means that if somebody is in horrible pain and he or she says, ‘I want to die. I want to die *now*,’ I don’t believe much that this is a free choice of a patient. This is an ethically very difficult situation. But I don’t believe it is free choice for the patient.

“First, I would try to control the pain. And not only controlling pain. Controlling pain in our society is so important. But not only this. There is a kind of pain in your soul, a pain of existence and many, many other problems, symptoms—not only pain. But if you try to control pain and comfort people, most of them—not all, but most of them—will say three days later, ‘Doctor, this is exactly what I want.’ And that’s the biggest reward to us. And this we see happening daily."

Though some euthanasia and physician-assisted suicide regulations specify that the patient must have a diagnosis of a certain number of weeks left to live, Dr. Zylich agrees with surveys indicating that physicians are poor prognosticators of length of life.

“We can never say it is three weeks or three months. And this is also what I feel the sanctity of life—you may never say how long it will be. In our hands…it’s so strange; you think somebody will die within one week and he lives three or four months.”

“You cannot idealize it or romanticize it to make a beautiful picture. Because sometimes it’s horrible. Sometimes we face horrible problems, horrible things which are not so easy. But this is what we are for; the whole team is working in this same direction.

Binding up “soul wounds”

"The second important issue in this third level is that what we are doing for the patients, half of it we are doing for the patient himself and half is for the family who need to carry the loss. And the way people die—if they die in pain or suffocate or whatever is happening with them—makes an enormous impact on how the children or the partners or whoever will die themselves twenty or thirty years later.

"This means that people who are coming here are full of psychotraumas, full of problems that sometimes were kept down, kept closed for many, many years. But when people are terminally ill, these ‘soul wounds’ are getting opened and they matter in the last phase of life. We think that if you provide a good palliative care at the end of life, you can help the future generation—people who will die later. They will die better because they will have had a better experience in the past. So that is an idea not only for the patient, not only for the students, but also for the future generation.

"And this is one of the reasons why we cannot say at the moment, ‘With perfect palliative care, we can cut all euthanasia wishes.' Because people are full of this experience from the past. And this is a very important factor why people will not dare to die naturally or have other ideas.

"For example, they have a tumor on a big toe, but they are afraid to suffocate, which never happens in this disease. When you ask what happened, they say, ‘My partner died ten years ago from bronchial cancer and he suffocated.' This is a kind of trauma they will never go through again. But they associate these things all together.

So the idea is that on the third level—and this is very long-term effect, but a very important task to do—is to prevent these kinds of psychotraumas. To assimilate death and dying and to facilitate this assimilation in society so they can carry on in a different way.

Condemning condemnation

"However, I must say, I am also very much critical of what Christians are doing and saying. I try to keep it reasonable, rational in the mind. But I still believe that what I am doing—everything—is influenced by this [religious faith]. But I am also critical of some things. I mean, church influenced society for a long time by forbidding. Some things were forbidden. Some things were good and bad. I think in modern societies—in Holland, this is my criticism—forbidding euthanasia is not possible anymore. The more you forbid, the more you get just the opposite effect. And the role of the church will be still weaker if you keep on in this way.

"So my idea is not to keep doing this in the twenty-first century, but just to teach doctors about good care. Just to teach students to develop good care. Show outside what is good; don’t just forbid it—you must do this or not do that—but by providing good care.

"Why? Because most of our patients here are not believing, not associated with any church. Are we ethically allowed to put on them our own beliefs, our own what we are convinced about? I think the more neutral is to just show models of the good care, to provide good care. And this will do a lot of good, I think, without polarizing.

"One of the biggest problems I have with all the situation in Holland is that the whole discussion about euthanasia is very much polarized. People fight with each other. It is much weaker now; it is much less polarized now. I think I also contributed to this. In this situation, we can better talk with each other instead of fight."

A prisoner reconciles with his dying mother

What do dying patients need to do before they die?

“I think to say goodbye to everybody whom they love,” responds Dr. Zylich. "This is very important. [In theory] it is very easy to say goodbye, but in practice, it is much more difficult. I mean, saying goodbye is to part away, to say also to forgive each other for many things which have happened."

Dr. Zylich points to a recent example of a dying woman estranged from her incarcerated son.

“I remember two weeks ago, we had an old lady who came here. She had been alone at home. She told us she had two children—a daughter and a son. The son was in a prison, together with his wife, (for something; we never heard what it was). But it was a very long sentence.”

Meanwhile, the bond between mother and son remained shattered.

“The lady couldn’t die here without seeing him—without forgiving him,” Dr. Zylich recalls. “So we called the judge, and we said, ‘We need to know if he wants to see his mother.’ And initially, he didn’t want to. He said, ‘No, it is closed. I don’t want to.’ But he didn’t even know—he didn’t realize his mother was dying. So we called once again. And the judge said, ‘Okay, start the procedure, but it will take at least one week before we can have all the papers.’”

But Dr. Zylich and his staff wouldn’t submit to the judge’s deadline.

“We said, ‘No, it cannot be one week. We need to have it tomorrow, just before the weekend.’ His mother couldn’t die without seeing him, but she was dying. And this is the biggest drama that we can imagine in hospice.”

Meanwhile, Dr. Zylich’s secretary got busy on the phone, reaching as high as the Minister of Justice. Finally, the system buckled to the tenacity of the hospice.

The next day, the incarcerated son arrived, shackled to prevent an escape. In a contrast to the serene hospice setting, a full contingent of prison guards and police escorted the prisoner in to see his mother. Wide-eyed hospice staff and patients stood at a distance as the son and his mother had a private meeting.

While Dr. Zylich does not know what exactly transpired between the two, he says, “They didn’t need to say much; she was so happy, really. This was beautiful. I mean, I think it meant something for him. Also, her daughter who was beside her was also very, very happy.

"If this had not happened—if she had not seen her son—it would have been a tragedy, I think for both. This lady was very, very happy about this. And she said, ‘Now I can die.’

“She died the next day.”

Teaching others to minister

The second aim of Rozenheuvel, Dr. Zylich explains, is teaching.

“What we are learning from our patients, we try to bring back to society in teaching.” Dr. Zylich teaches at the nearby Catholic University in Nijmegen, offering about 400 hours of lectures to post graduate students, general practitioners in training, and nursing home physicians in training. He also frequents churches, meetings with groups of older people, and nursing homes.

When the Netherlands began to tolerate and then promote euthanasia, palliative care and hospice lagged far behind the rest of the developing world. Today, Holland remains relatively alone in sanctioning medical killing, and it has keenly felt the sting of world criticism and the embarrassment of deficiency in truly compassionate alternatives. As a result, doctors are flocking to Dr. Zylich for help and looking to Rozenheuvel as an example.

“It’s really an enormous change,” Dr. Zylich states. “The interest in what palliative medicine is, what we are doing in hospice, the care for the patient, is growing daily. Five years ago, if I were to give a lecture to the general practitioners, I would have had ten people in the room listening. Three months ago, we launched a three-day course for general practitioners and we had 800 applicants for 25 spaces. Now that’s a difference.

“The problem we are facing now is that we do not have enough teachers, experienced people to teach. They realize now that they need to know something. They realize that they are missing something. They’re looking for it.”

Nursing homes inhibited hospice

Dr. Zylich notes that palliative care education in Holland “is developing now very, very fast. Why? First of all, we were far behind.

"Some people will not like what I say. Nursing homes inhibited the development of palliative care for many, many years. Because they said, ‘We are doing this and in the right way.’ Until now, nursing homes were providing ‘care for the dying.’ This was the standard cliché. People who cannot be at home, taken care of their family and General Practitioner; they will go to a nursing home. But nursing homes are full. They operate with a bed occupancy of 100 percent. So they have a long waiting list. Sometimes you have to wait two or three months before you get in. If you are a psycho-geriatric patient, it can take six to eight months. Very unpractical.”

“So now we find ourselves far behind. And we realize that we need to do something else, something new.”

As a result of this realization, Dr. Zylich says nursing homes are finally working together with hospice.

"Cost is not the limiting factor in patients receiving adequate end-of-life care," Dr. Zylich explains. "Government-subsidized insurance pays the bulk of the cost; patients only pay about 25 guilders [approx. $15] for their food or basic needs. “The problem,” Dr. Zylich points out, “is that the [nursing home] houses are full. They are very inflexible.”

Dr. Zylich observes, “Most patients want to die at home. They try this. But when they fail, they need to be admitted immediately. At that moment, they cannot wait a month. They need to be admitted the same day or the next day. And nursing homes are not providing this kind of flexibility.

"So the market is very limited. They take care of outpatients in the long term dying with diseases that will cause death between six months to a year. But most of the diseases … people nowadays are very active and can do everything until three weeks before death. That’s the flexibility we need.

"So what we are doing with hospice is taking care of the people at home. To support them at home, and if that is not possible, to admit them here. Twenty to thirty years ago, [Dutch] nursing homes were unique. Very modern. Not very many countries in the world had this kind of network that we had. So we were forward in developing care of older people. But it was not enough. People want to die at home. They want to have flexibility. So this progress was not enough.

“This experience from the past [has had an] enormous impact on euthanasia. This is one part of the problem in euthanasia. [Dutch have] a modern, New Age idea of comfortable death--a "good" death that can be planned. These two things together, I think, make euthanasia very acceptable in this country. [Now] many, many people in this country cannot imagine medicine without euthanasia."

Euthanasia-entrenched government eyes palliative care

While Dr. Zylich enthusiastically embraces Holland’s newfound interest in palliative care and hospice, he views the government’s interest with caution.

“Many people think that palliative care and euthanasia can go together,” he observes. “Including our Minster of Health,” who reportedly attempted to divert end-of-life educational funds intended for palliative care to euthanasia instead.

“There is a big [concern] from one side that if we develop good palliative care, the need for euthanasia will go down,” Dr. Zylich explains incredulously. Yet he admits that the total eradication of euthanasia in Dutch society remains illusory, even as people recognize the benefits of hospice.

"It will not be absolutely reduced to zero; I'm sure about this. But it will go down." Dr. Zylich also fears that government interference would undoubtedly accompany government subsidy.

"One of the biggest dangers I feel is that we will get money from the government to do our work in hospices. So in return, they will expect us to change our ideals. We need to keep our ideals. That's important."

Battling the culture of death

The third aim of the hospice is cultural impact—what Dr. Zylich refers to as "forming of a culture and making people more aware of problems of death and dying." That impact begins with patients and their family members and extends to the culture at large.

"We try to invite, for example, children and grandchildren of our patients," he explains. "They come on the weekend, and we have some facilities for children here. They need to see their grandfather or grandmother in peace. They need to be present here. They cannot be put aside and told, 'It's so horrible; never think about it.' They need to be here. They need to see their grandparents without pain. They can talk with them, communicate with them, even two or three days before death—right before death."

As far as impacting the Dutch culture of death, Dr. Zylich paints a disturbing picture of the future in the Netherlands.

"What I see also in mainstream medicine is that the possibility of curative medicine is at the moment at a plateau. They are not increasing any more. The costs are increasing, but not the possibilities of cures. So because of this enormous number of older people coming, there will be much more interest in these problems, in quality of life, and in preventing many things at the end of life.

"What I see happening is that it is inevitable that euthanasia will go on. If you look at the demographical changes and our potential to take care of the growing army of older people, in all the developed countries, this will be inevitable.

"It will also be inevitable, very important, to increase the opposition against this just to counterbalance it. So I think there will be a lot of need for hospices, a lot of need for palliative care—much more than before. But it will be always together with, or beside, euthanasia. And I hope that in the future we will be able to counterbalance this movement. But I don't see the possibility that we would prevail and people would say, 'Euthanasia is not necessary; let us all do [hospice].' It's not very realistic."

"So I will never be without work, I think, in twenty years! But I am not so optimistic. In Holland, before I will go with my pension 20 years from now, there will be 85 percent more people dying from cancer—progress in oncology or not. So it will nearly double. The number of hands to care for these people—young people who will be able to care for these older people—will decrease by 30 percent.

"This is dramatic. I do not have an answer for this. Palliative care is very labor-intensive. You need to have a lot of hands. I am not so optimistic about this. And this would be the reason for many people in 20 years why euthanasia would be so important. It will be in 20 years much, much more important than it is now.

"And we need to be prepared for this with our ideals, with our institutions. For example, we try now to prevent euthanasia 20 years from now—by making people more aware. Maybe it is just a droplet in a whole ocean, but it is important."

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[i] Based on an interview conducted by the author with Dr. Zbigniew Zylich on February 11, 2000 at Hospice Rozenheuvel in Arnhem, Netherlands.

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