Lessons from a courageous dying patient
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The atypical reaction of a patient to the news of her terminal illness raises a number of questions about care for the dying.

Some death-related issues cause controversy in the medical profession as well as in the general public. Questions related to death in particular are the subject of many arguments, and the principle of telling the patient the truth is not universally upheld, especially when it comes to deciding whether to withhold life support. In Lebanon mercy killing is prohibited, and telling terminal patients about their prognosis is unusual. The rationale here is not to distress a fragile person. In an unpublished study, Hamadeh et al. found that 53% of Lebanese doctors preferred not to inform their patients about their illness when they were diagnosed to have cancer.

The patient

The patient who is the subject of this article is Mrs S, who was 66 years old, Lebanese and Muslim Sunni. She presented to the American University of Beirut Medical Center with a history of increased abdominal girth of one month’s duration. She was pale-looking but in no distress. On physical examination, a positive fluid wave and decreased left air entry were detected in the abdomen and lungs. Her hematocrit was 27%. A CT scan showed left adnexal mass extending into the pelvis, involving the rectum and the omentum with ascites. A chest X-ray revealed left pleural effusion. Cytological evaluation of the ascitic fluid showed adenocarcinoma consistent with ovarian primary cancer.

On being told by her daughter about the diagnosis, she reacted calmly. She said she had a full life and that she cared more for the quality of life than for longevity. A gynaecologist oncologist interviewed her three times in the course of two days, but despite extensive counselling she refused all treatment options. These included aggressive surgical debulking of the tumor followed by chemotherapy. Instead, she discussed issues related to inheritance, organ donation, euthanasia, and the cremation of her body.

Following her discharge, she finalized the documents needed to transfer her possessions to her 34-year-old single daughter who works as a secretary. She informed her well-to-do son about this arrangement, and signed the forms needed for donating her eyes for corneal transplantation. The treating physician contacted the hospital lawyer to know the requirements for cremating her body after death. A notary’s signature is usually all that is required in Lebanon for such matters, but in this case four notaries from different religions were contacted and refused to sign, since crema-
tion is not approved by the religions officially recognized in Lebanon. It is the religious affiliation which dictates what is done with the body after death.

At the patient’s home, about 600 cc of ascitic fluid were removed, for palliation, every 3 weeks. During this three-month period she was relaxed, and spent much of her time reading novels and doing crossword puzzles. When she was no longer able to get about and take care of herself, she asked to be taken to the hospital. In the hospital she again insisted on receiving no treatment other than analgesics. She was interviewed by a psychiatrist who found her fully aware of her condition, and the consequences of treatment or no treatment.

After 12 days in the hospital the patient passed away. By her side were her son, her daughter, her sister, and two brothers. The family had supported the patient’s “no treatment” option. When a letter of appreciation from the eye bank arrived, they were happy to learn that the sight of two people had been preserved by means of their relative’s gift.

Issues raised by the patient

The wishes and behaviour of this dying patient may not surprise a doctor practising in a developed country, but they would be regarded as unusual in the Middle East. The case illustrates a number of psychological and ethical questions which arise more and more frequently in terminal care.

- How do people react to the prospect of their own imminent death? Many people who know that they have a terminal illness have been observed to pass through five stages: denial, anger, bargaining, depression, and acceptance (1). However, experts disagree about these stages, and there are many variations. In a study on patients newly diagnosed to have Hodgkin disease and melanoma, 47% expressed denial over a six month period (2). What is noteworthy in this case is that Mrs S appears to have gone directly to the fifth stage, fully accepting her impending death in less than 24 hours.

- What are the ethical options regarding treatment? The decision to allow the disease to take its course was based on the patient’s wish, the poor prognosis for a cure, the support of the family for the “no treatment” option, and the desire not to prolong the agony of the patient and the family. The Lebanese law states that the physician should respect the will of the patient (3). It instructs physicians to reduce physical and psychological suffering, and warns both against euthanasia and against “heroic” measures to prolong the life of a terminally ill patient.

- How should issues of organ donation be settled? The donation of organs for transplantation is approved by both Christianity and Islam. Sunni and Shia scholars in the United Kingdom accept

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the view that where brain death is certified organs can be recovered for this purpose. They add that in the absence of a donor card the next of kin
may give permission to remove organs from the body to save other lives (4). However, physicians in Lebanon usually fail to discuss organ donation with the relatives of potential donors. Abou Joude et al. reported that out of 11 dying patients in hospitals in Lebanon, the families of only three were informed by the treating physician about the prognosis (3). Though obviously it requires great sensitivity, discussing organ donation with the family of a dying patient should not be regarded as impossible by the medical team. In fact, as was the case here, it can be a source of consolation to the bereaved family. With the increasing number of patients waiting for a suitable organ to be transplanted, physicians have a duty to educate patients and families about organ donation.

- Is the patient better cared for at home or in hospital? One guiding principle for dealing with terminally ill patients is to recognize their needs. Dying patients express fear of pain, becoming dependent, and being neglected physically or emotionally. Mrs S chose the home environment till she was unable to care for herself. At that point she felt that by staying at home she would burden her family. Some residents and medical students at the hospital felt that this patient should have been kept at home, but for this certain conditions had to be met. Among these are suitable accommodation, family support, help at home and a palliative care home support team capable of providing both day-to-day care and a rapid response to emergencies. In the absence of such support, hospitalization is often needed, especially when outpatient pain control fails. In many developing countries such as Lebanon, there are no home support teams for palliative care. With the rise of chronic diseases and AIDS as leading causes of death, together with the high cost of hospital care, we can expect the number of those who will spend their last days at home to increase. Serious efforts should therefore be made to provide for palliative home care in Lebanon and other developing countries. There is more to medicine than curing; it is also caring, and more emphasis should probably be placed on teaching medical students how to look after the terminally ill patient.

- Can patients ensure that their wishes are respected? In contrast to Lebanon, the practice in many industrialized countries is to inform patients about their terminal illness and the ultimate prognosis, thus upholding their right to self-determination. To protect this right in the event of loss of competence, anyone who wishes to can fill in an advance directives form before such loss occurs. This practice can also be of great help to the medical team, which otherwise may be forced to make life-and-death decisions on behalf of patients without knowing their views on the matter. Advance directive forms usually cover the wishes of the patient regarding cardiopulmonary resuscitation, mechanical ventilation, dialysis, surgery, blood transfusion, antibiotic therapy, and nutrition. Some also include sections on organ donation, place of death (home or hospital), and what should be done with the body after death. To be of real use, an advance directive form has to be supported by the law. In the United States, all federally funded health care facilities are required to urge patients to complete such a form on admission to hospital. Health care professionals have to respect the wishes
of the patient as indicated in the form even when a close relative disagrees. In Lebanon, such regulations do not exist and physicians have to weigh the merits of each argument as it arises.

To sum up, there is a need to teach medical students and physicians about the proper care of terminally ill patients. Medical personnel should learn to be both sensitive and at ease while discussing issues related to death, including organ donation. Last but not least, there should be serious efforts to develop palliative care home support in developing countries.

References

Help from nurses for lay carers

In the next century individuals, families and communities will play a larger role both in determining and in meeting their own health needs. The roles of nurses and other health care providers will change as individual behaviour and lifestyle choices are seen as more important for health. With increasing numbers of elderly and children, a range of informal care-givers will be needed. Everyone may need to be taught the basic skills and knowledge of caring, and everyone will be involved in matters relating to health. Traditional labels such as qualified/unqualified care-givers of formal/informal care will be less important than they are today. Providers of care must seek partnerships with communities to help them plan and implement health services so as to ensure an equitable distribution of health care. . . . Nurses will help people to help themselves and will do for people what they cannot do for themselves.