

In Memory of my Mom, Sarah Cohen (1930-2011)

## **Fatal Choices and Flawed Decisions at the End-of-Life: Lessons from Israel**

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### **Abstract**

The article opens by presenting a recent disconcerting event that took place at a rehabilitative nursing home in Tel Aviv. Next I will discuss the Dying Patient Law which came into effect in 2005. I will then move on to probe the double effect doctrine as it is relevant to the case at hand, and the role of the medical profession and of the family in making decisions at the end of life. It is argued that patients who express a wish to die should receive a comprehensive care addressing their physical and mental condition before rushing to provide lethal medication. Medicine is a healing profession, a caring profession. I conclude by offering some guidelines to help practitioners address the intricate questions they face when patients ask to die.

**Keywords:** Israel Dying Patient Law, nursing home, care, communication, palliation, double effect, family, patient's best interests

### **Introduction**

The article opens by presenting a recent disconcerting event that took place at a rehabilitative nursing home in Tel Aviv. Next I will discuss the Dying Patient Law which came into effect in 2005. As I was one of the people who drafted the law, I have intimate knowledge with the legislation process. I will then move on to probe the double effect doctrine as it is relevant to the case at hand, and the role of the medical profession and of

the family in making decisions at the end of life. It is further argued that patients who express a wish to die should receive a comprehensive care addressing their physical *and* mental condition before rushing to provide lethal medication. Medicine is a healing profession, a caring profession. I conclude by offering some guidelines to help practitioners address the intricate questions they face when patients ask to die.

### **Case Study**

SC was an 80 year old Israeli woman. She suffered from multiple chronic conditions, including heart disease, pulmonary congestion, chronic leukemia, diabetes and high blood pressure. She received medication to treat her medical condition. Her pressing problems were shortness of breath and severe pain in her left leg, the result of poor blood circulation. SC resided in a rehabilitative nursing home in Tel Aviv. One night she could not sleep. She sat on her bed, unable to lie down and screamed with pain. A nurse came and gave her some analgesics with no relief of her pain. The following day the institution's social worker visited her. SC sat in the dining hall with her older sister CA. The social worker asked SC how she felt. SC replied she did not feel well. She was tired and in severe pain. The social worker asked: What do you want? SC answered laconically: To die. The social worker then proposed to categorize SC as a "terminal patient" with the implication that SC will receive from that time only hospice care. That is to say, SC will receive only pain relief medication and no treatment aimed to heal or improve her health. SC agreed. She signed a document to that effect. Her sister CA served as a witness. Shortly thereafter SC received significant dosages of morphine. She lost her appetite, became bed ridden, and quickly lost the ability to communicate. SC became incoherent, confused and hallucinated. SC, who was not a dying patient, quickly became a dying patient.

This case study poses some serious legal, medical and ethical questions. Let me first reflect on the Dying Patient Law.

### **The Dying Patient Law**

In 2000, the ministry of health assembled a group of 59 professionals to draft a law to administer end of life decision-making. The Dying Patient Committee, known also as the Steinberg Committee after its Chairperson, Professor Avraham Steinberg, worked for two years and submitted its recommendations and draft law to the government. The Committee considered titling the law "The Terminal Patient Law" but the philosophers of the committee objected, arguing that the term "terminal" does not serve the best interests of the patient. They insisted on a lucid end-of-life language, on terminology that would make it clear that the law was applicable only to patients whose death is near.

The Dying Patient Law came into effect on December 6, 2005. The Law applies only to patients who were categorized by a qualified physician as "dying," and who have specifically expressed a wish regarding their treatment, either its prolongation or cessation. The Law assumes that the majority of people do not wish to die. All Committee members – including physicians, ethicists and religious authorities – were of the opinion that patients tend to prefer life with medical challenges over death.<sup>2</sup> The law was aimed to strike a balance between the principles of value of life and autonomy, based upon the value system of Israel as a Jewish-democratic state. The Law stipulates that decisions concerning dying patients should be based on the patient's medical condition, her wishes and the degree of her suffering. A "dying patient" is defined as a person who suffers from an incurable illness and who has no more than six months to live even with medical therapy; the last period of two weeks of expected life is defined as the final stage (The Dying Patient Law, Chapter D, Section 8). The Law specifies the means to guarantee that patients have explicitly wished to die. In instances where no instructions have been left, a guardian or a person close to the patient is allowed to make a statement regarding her or his desires. The statement is only advisory and not binding. The Law further stipulates that minors under the age of 17 will be represented by their parents on the issue of ceasing treatment. If a conflict between the parents and the physician arises, a committee will rule on the matter (The Dying Patient Law, Chapter D, Section 28; Barilan 2007).

The Law only pertains to patients who are competent or were once competent. It

does not apply to Post-Coma Unawareness patients (PCU) (Cohen-Almagor 1997),<sup>3</sup> those suffering from severe pain and suffering, non-terminally ill but seriously malformed neonates or never competent patients. The Law prohibits withdrawal of continuous care, distinguishing between intermittent and continuous care. The distinction was made due to the clear difference between the philosophers of the committee and its religious members on the legitimacy of withholding and withdrawing treatment. While the philosophers thought that there was no morally significant difference between withholding and withdrawing treatment, all representatives of religious denominations, without an exception, strongly opposed to withdrawal of treatment. Thus the distinction between intermittent and continuous care was aimed to address an important aspect of Jewish (Halachic) law. Under Jewish law, patients cannot be disconnected from ventilators (“killing”).

However, there is no problem in not connecting them to such machines (“letting die”). Continuous treatment has no intervals. It is defined as any form of treatment that is essentially uninterrupted and when there is no clear distinction between the end of one cycle and the beginning of another. “Intermittent treatment” is defined as treatment that begins and ends in well-defined cycles. Mechanical ventilation is an example of continuous treatment, while intubation, surgery, blood transfusions, dialysis, chemotherapy, radiotherapy or antibiotics are examples of intermittent treatment. According to the Law, it is forbidden to terminate continuous medical treatment, unless it is done for the purpose of medical treatment. However, it is permitted to terminate discrete treatment. A patient may therefore request not to renew discrete treatment that has been interrupted, but she cannot request to withdraw continuous treatment, e.g. mechanical ventilation (Ravitsky 2005; Gross and Ravitsky 2003; Steinberg 2001).

The Law also distinguishes between primary medical care (medical care to treat the terminal disease itself) and ancillary care (antibiotics for infections, food and fluids, etc.). Incompetent terminally ill patients have the right to refuse any primary treatment but may not refuse ancillary treatment. End state terminally ill patients may refuse any primary treatment

or ancillary treatment. Patients can refuse food and fluids if competent. Incompetent patients receive food and fluids despite previous contrary statements. This is because food and fluids are regarded as a basic need of any human being. They are not perceived as treatment. Thus patients must receive food and fluids unless the attending physicians determine that food and fluids cause harm or suffering. Furthermore, the law explicitly prohibits euthanasia and physician-assisted suicide (PAS) (The Dying Patient Law, Chapter D). No Committee member endorsed euthanasia while only one member supported PAS. The prevailing view was that Israel as a Jewish-democratic state should not allow physicians to practice euthanasia and PAS. Some committee members thought that in the future the prohibition may be reconsidered but not at the dawn of the 21<sup>st</sup> Century.

The Law requires the appointment of a senior physician as the responsible health-care provider. Her tasks are to establish the medical situation of the patient; to analyze all relevant facts and documents together with all other experts and decision-makers; to establish the wishes of the patient; to formulate a detailed plan of treatment; to document all the decisions in a comprehensible and explicit manner; and to inform all relevant parties of the decisions. Decisions should be based on medical facts and the patient's wishes (Steinberg and Sprung 2006, p. 1236).

Finally, the Law provides for advance directives and the document that patients should use. It establishes detailed mechanisms for taking into account the calculated wishes of the now incompetent dying patient. They include a detailed form to be filled out by the person with the aid of a physician or nurse; renewal of the statement every five years; re-evaluation of the statement when diagnosed with a serious illness, with the aid of an expert physician, and the establishment of a national pool of advanced medical directives (The Dying Patient Law, Chapter E).

#### *Relevance of the Dying Patient Law to the case at hand*

To what extent is the Dying Patient Law relevant to the case at hand? SC did not suffer from *any* incurable disease. All her ailments were treatable. No senior physician was present in

her discussion with the social worker, verifying that she wished to die. No senior physician advised her of a detailed plan of treatment. It seems that her decision was probably related to her continued suffering from pain which was not adequately treated and probably could have been if given the chance.

The Law stipulates that the attending physician should do whatever possible to relieve the patient's pain and suffering by medication, palliative care or psychological means (The Dying Patient Law, Chapter D, Section 23). No psychological treatment was offered to SC. No palliative care specialist saw her.

A few weeks prior to the fatal discussion that SC had with the social worker she completed another form. In that form, SC designated her son RC as her medical guardian with whom the nursing home medical team should consult should she become incompetent. As RC resided in England, the social worker advised SC to nominate another person, an Israeli resident, as a second medical guardian. This is because the social worker argued that medical directives should be signed in person. They cannot be faxed or delivered orally over the phone. SC then added her sister CA as a second guardian, stipulating that in any event CA needed to consult with SC's son, RC, on any decision concerning SC's health. Copies of this document, with the specific stipulations, were made and given to SC, RC, CA and the social worker. Yet, only a few weeks later SC was advised to sign another document. RC was not informed or advised, in absolute disregard for the previous agreement and signed advanced directives.

Thus, the law was not upheld. The procedure that the nursing home pursued is known as the double effect doctrine. The Dying Patient Law says nothing about the double effect doctrine. Very little deliberation was conducted in the Committee about the doctrine despite its practice in hospitals and nursing homes. Let me now shed light on this common procedure and its problematic nature.

## **The Double Effect Doctrine**

The ethical concept of double effect is used to justify medical treatment designed to relieve suffering where death is supposedly an unintended, though foreseeable, consequence. It comes from “the double effect” doctrine developed by Roman Catholic moral theologians in the Middle Ages as a response to situations requiring actions in which it is impossible to avoid all harmful consequences. The doctrine makes intention in the mind of the doctor a crucial factor in judging the moral correctness of the doctor’s action because of the Roman Catholic teaching that it is never permissible to “intend” the death of an “innocent person.” An innocent person is one who has not forfeited the right to life by the way he or she behaves, e.g., by threatening or taking the lives of others (Anderson 2007; Boyle 2008; Cohen-Almagor 2001; Kamm 1999; McIntyre 2001; Quill, Dresser and Brock 1997; Sulmasy 1999; Woodward 2001).

The double-effect reasoning may permit an act causing good and evil when it meets the following conditions:

1. The act considered independently of its evil effect is not in itself wrong. It must be morally good or at least indifferent;
2. The agent intends the good and does not intend the evil either as an end or as a means; however, the agent may permit the bad effect;
3. Application of the doctrine presuppose that some kind of proportionality condition has been satisfied: The agent has proportionately grave reasons for acting, addressing his relevant obligations, comparing the consequences, and, considering the necessity of the evil, exercising due care to eliminate or mitigate it;
4. The good effect must flow from the action at least immediately as the bad effect;
5. The good effect must be sufficiently desirable to compensate for the allowing of the bad effect (Cavanaugh 2006).

In other words, the double effect doctrine applies if the desired outcome is judged to be “good” (e.g. relief of suffering); the “bad” outcome (e.g. death of patient) is not intended; the “good” outcome is not achieved by means of the “bad,” and the “good” outcome

outweighs the “bad.” However, both the intention and the proportionality presuppositions are problematic. It is hard to know, or to prove, what is the doctor’s intention, and the issue of proportionality is tricky as “proportionate” medication is not easy to evaluate. The double effect doctrine is a different terminology and also a practical way to deal with severely ill patients. Some physicians prescribe large doses of medication knowing that, as a result, the suffering will be lessened but also that life may be shortened. They feel comfortable with what they are doing: they are not breaking the law; they are acting in accordance with their medical understanding and providing solace to suffering patients. The double effect doctrine might not be altogether sincere because there is no clear-cut distinction between treatment administered to relieve pain and suffering, and treatment intended to shorten the dying process.

A recent study found a striking ambiguity and uncertainty regarding intentions amongst doctors. Some were explicit in describing a “grey” area between palliation and euthanasia, or a continuum between the two. Not one of the respondents was consistent in distinguishing between a foreseen death and an intended death. A major theme was that “slow euthanasia” may be more psychologically acceptable to doctors than active voluntary euthanasia by injection, partly because the former would usually only result in a small loss of “time” for patients already very close to death, but also because of the desirable ambiguities surrounding causation and intention when an infusion of analgesics and sedatives is used (Douglas, Kerridge and Ankeny 2008).<sup>4</sup>

In the case at hand, the side effect of hastening death was an inevitable or at least likely result of the administration of opioids in order to relieve SC’s pain. The hastening of death was not an unwelcomed side effect of providing pain relief in the context of palliative care. However, the *intention* was to kill the patient because the patient wished to die and the medical team apparently thought that there was no point in prolonging her life. SC confirmed this later on in a private conversation. The double effect doctrine was misapplied because less harmful alternatives were available, because the intention was not merely to relieve

pain, and because hastening death was done prematurely, out of proportion to the medical condition of the patient.

SC was a determined, strong-willed person, very energetic and active. Until a few weeks before, she resided in her own apartment in Tel Aviv, catering for herself and her personal helper. Overall, she led independent life. She used to cook, shop, travel by public transportation, play bridge, go to restaurants, meet family and friends. Suddenly she found herself confined to a rehabilitative nursing home, no longer able to climb the stairs to her apartment on the second floor. She could hardly walk, moved about only by a wheelchair, and had to wear an oxygen mask. She found it difficult to cope, and to accept the debilitating change. Loneliness, bitterness and pain became more common than peace, tranquility and joy. What she needed was a psychological counseling that could help her find new meanings in life and a way out of her depression. But instead of appropriate counseling to improve her quality of life and her general mood, the social worker rushed to advise her hospice care which was bound to lead to her death, death she wished.

### **The Role of the Medical Professionals**

The rehabilitative nursing home where SC was residing did not have an in-house psychologist. The social worker assumed this role as well. She did not have any qualifications to provide counseling and appropriate psychological care for patients.<sup>5</sup> This was a major omission that should have been corrected. The nursing home is considered one of the best in the country. Patients pay a lot of money to receive private care and therapy but the rehabilitation model is confined only to the physical aspects of the body. The mental, spiritual aspects are neglected. There are strong links between mind and body; caring for one cannot be done adequately without addressing the other. Both aspects of care, physical and mental, are crucial for successful treatment.

The astonishing thing was that SC voiced her death wish once, and this was enough for the social worker to accept. There was no argument, no debate, no other choices offered; no asking or evaluating whether SC was depressed and why she wished to end her life. SC

expressed a wish to die and then made her fatal choice to accept only hospice care, which meant morphine. But no medical professional had ever explained her medical condition to SC, what were the possible options and courses for treatment, what could have been done to address her needs and concerns. Instead of providing reassurances in the value of life, the social worker was quick to agree to terminate the healing treatment.<sup>6</sup> The role of the social worker as a facilitator is to create an open, safe, caring and supportive space for the patient. By “supportive” it is not meant to support all that the patient wants without any questions. I believe that the social worker consulted senior physicians, but none came to speak to SC. This is a clear violation of Israel’s Patient’s Rights Act (1996) that established the right of patients to be informed of diagnosis, prognosis and treatment related to the medical condition. The Act obligates the patient’s physician to provide the medical information (Patient’s Rights Act 1996, <http://waml.haifa.ac.il/index/reference/legislation/israel/israel1.htm>). SC agreed to accept only hospice care but she did not fully understand the implications of her fatal consent. Furthermore, patients cannot be said to give informed consent when they are very depressed, very frail or confused. The short conversation with the social worker at the end of which she signed the fatal document cannot be described as one in which the patient gave her informed consent (Faden and Beauchamp 1986; O’Neill 2003; Manson and O’Neill 2007; Maclean 2009; Brennan, 1991, chap. 5; Grisso and Applebaum 1998; Switankowsky 1998; Wear 1998). This was a mockery of the healing process and of a careful decision-making process. It is shocking that such a quick procedure can happen in Israel nowadays, a country known for its rigorous care and intensive treatment at the end of life.<sup>7</sup>

SC did not have one thorough conversation with her medical doctors about her condition. When she was asked to fill the medical guardianship forms, she believed she was about to die. She increasingly felt that she had constituted a burden on her family, and that her medical condition was bound to deteriorate. No medical professional provided her hope and assurance that she would be able to overcome the physical challenges.

Medical professionals should resort to the language of hope, especially when dealing

with older patients with multiple chronic conditions. The language of hope includes various attributes, among them positive expectations; personal qualities; spirituality; patient's goals; comfort; help/caring; interpersonal relationships; control; one's legacy, and life review (Johnson 2007). Already vulnerable when they learn they have a life-threatening disease or chronic illness, patients can feel bewildered. The power of direct communication, of choices offered, of the language one is using, is profound. The way options are presented can have detrimental effects on the decisions patients make. Indeed, efforts have been made across the medical community to grapple with the language and ethics of hope. A consensus is emerging that all patients need hope, and that doctors are obligated to offer it, in some form or another (Nathan 2010; Contreras and Kennedy 2009; Hoffman 2005). In *The Anatomy of Hope*, Jerome Groopman (2003) asserted forcefully: "Clear-eyed hope gives us the courage to confront our circumstances and the capacity to surmount them. For all my patients, hope, true hope, has proved as important as any medication I might prescribe or any procedure I might perform."

I believe in phenomenology, that we shape our lives by the words we choose. The invocation of concepts and the terminology we use have significant implications on the care of patients. The medical professionals at the rehabilitation nursing home used the exact language that members of the Steinberg Committee dismissed. Offering a patient to be defined as "terminal" does not serve the patient's best interest. When a patient is categorized as "terminal," the message is one of no hope, of surrender, of despair. When patients are diagnosed as "terminal," it may seem that the medical professionals are counting the patients' days, and are discouraging them from fighting for their lives. SC asked to die and immediately was offered to be categorized as "terminal" by a social worker, not even by a qualified physician. This was travesty of adequate medical care.

The medical professionals' task is not to hold a clock over the patients' heads and count their days. When the destiny of patients is in the hands of medical professionals who seem to have given up, the patients cease looking to their caregivers for assistance. Hope, I reiterate, is an important component of life, and loss of hope diminishes the will to fight for

life. I am not saying that medical professionals should lie. They must report the medical situation accurately to the patients and their beloved people, and not raise false hopes. But they should not smother the power of life by categorizing patients in terms that may weaken the will to live.<sup>8</sup>

In *Garry Lee v. Oregon* (1995, p. 13), the court said that even for physicians who specialize in treating a terminal disease, no precise definition is medically or legally possible, since only in hindsight is it known with certainty when someone is going to die. As the Ninth Circuit noted (in *Compassion in Dying*, 49 F. 3d, 1995, p. 590), the terminally ill category is “inherently unstable.”

#### *Moral conduct, immoral conduct, and amoral conduct*

In this context, I wish to distinguish between moral conduct, immoral conduct, and amoral conduct. Moral conduct perceives patients in the Kantian sense as ends rather than means, treating them with dignity, care and respect. An objective end, Immanuel Kant explains, is one for which there can be substituted no other end, for otherwise nothing of absolute value would be found anywhere (Kant 1969; Jost and Wuerth 2011). We respect patients as autonomous human beings who exercise self-determination. Each individual is perceived as a bearer of rights and a source of claims against other persons, able to make decisions as a free agent. To regard others with respect is to respect their right to make decisions regardless of our opinions of them. We simply respect the individual's reasoning, so long as she does not harm others. We respect her rights as a person even we disagree with her specific decisions and choices.

Immoral conduct is one that is blatantly uncaring, disrespectful and undignified. Immoral decisions and conduct are in opposition to what is deemed right and ethical. Amoral conduct is practiced when people are not aware that they transgress ethical boundaries. They are oblivious to ethical standards as no one ever taught them the philosophical and ethical skills required for the job. They are not sensitive to the fact that their conduct may have deleterious effects on others.

My own research over the past twenty years in seven countries and dozens of hospitals and medical centers show that a great deal of the medical professionals' conduct is amoral in nature. Many medical professionals are superficially familiar with their professional ethical code of practice as they received only limited training and failed to fully comprehend the intricate philosophical layers underpinning their ethical code. The situation could be very different were they to receive adequate education, pointing to the ethical issues at hand, making them aware of moral quandaries and ways to address and resolve them. Medical schools should invest in teaching, planning, and developing medical ethics courses and communication skills programs in undergraduate, residency, and continuing medical education, in order to shape new role-models for the next generation of medical professionals. We need to create a culture of compassion, empathy, and honesty, compassionately diffuse distress and despair, and effectively address systemic barriers to care as they arise (Sears 2010; Wright, Sparks and O'Hair 2008; Kurtz, Silverman and Draper 2005; Heritage and Maynard 2006). Most importantly, we need to educate physicians to invest time in their patients, to sit (not stand) with them, talk to them at eye level, explain their condition to them in language they fathom, and understand their concerns, fears, wishes and motivations.

The Dying Patient Law requires certain procedural formalities regarding medical directives. The form must be signed in the presence of two impartial witnesses. In this case, there was one witness, CA, who clearly was not impartial. The form should be filled in after the signatory has received medical information from a qualified doctor or registered nurse who must write down the essence of the information (The Dying Patient Law, Chapter E, Section 32a). SC received no detailed information about her condition from anyone. She suffered for weeks from pain in her leg but no substantive treatment was given to her designed to heal the leg. Care is the bedrock of medical practice but all that SC was given was pain-relief medication.

SC's younger son, RC, called his mother from abroad each and every day, sometimes more than once a day. When he noticed that something was wrong, that he was

unable to communicate with his mother as before, he enquired about her condition with the medical staff. No one told him what was going on. At one point, SC told him she was about to die. Alarmed he called the nurse and asked why his mother spoke in this fashion. The nurse, in response, told him that SC was fine: She seemed to be happy, laughing, eating, and entertaining company. No word was uttered about the new morphine regime.

RC called the attending physician, Dr. N, who described his mother's condition as "stable." Dr. N did not tell him of the new morphine treatment. RC discovered this only a few days later, upon arriving in Israel and after his mother already had left the nursing home.

### **The Role of the Family**

SC had two sons. Her elder, YC, resided not far from Tel Aviv. He had problematic relationships with his mother and worked hard as an independent salesman. He visited his mother once a week. Her younger son, RC, had a close relationships with his mother but, as noted, he lived abroad. Apart from him, the closest person SC had was her sister, CA. However, CA was 83 year-old, with her own health problems including sever back problems that inhibited her free movement. CA was put in a very uncomfortable situation. On the one hand, she felt obliged to visit her close sister. On the other hand, each visit was quite difficult. She needed to take a bus, and then to walk with her cane to visit SC. Her conscience did not allow her to remain at home, but her physical abilities were deteriorating. Aiding her sister did not help her own health.

When SC approached CA and said she wanted to die, CA did not try to confront her sister and dissuade her. She was always willing to help her younger sister. SC asked her not to tell anyone. It was supposed to be their secret, conspired with the social worker. SC thought this was for the better. Her older son was not that interested in her; the other, who was interested, was far away and led his own life, with his family, abroad. SC found little meaning in life. She explained this to CA. CA, instead of providing solace and meaning in life, told her sister: I will join you. She legitimized SC's request and encouraged her to go ahead with her plan. As SC wanted to keep this secret, she had no qualms hiding this

development from RC, despite her written obligation to him and the document she had signed in which she pledged to consult and advise him of any medical development relating to his mother.

In many respects, SC had put her sister in an impossible situation. RC used to call his aunt CA for updates on a regular basis. Going ahead with the plan meant to hide this development from him. The trust between the two would have been destroyed forever. But if CA were to refuse her sister, that would have entailed a clash with SC, something CA wanted to avoid. After some hesitation, she cooperated with her sister.

This episode illustrates how dangerous it is to rely on one close relative for such fateful decisions. CA had her own partisan interests that were germane to the case. Those interests did not serve the patient's best interest. Being close to the patient does not necessarily mean that the patient's best interests are being served.

In some respects, the case at hand is reminiscent of the *In the Matter of Spring* (1979) case in the USA. This case involved an incompetent person whose wife petitioned the court for an order that hemodialysis treatments, which were sustaining the life of the ward, be terminated. Mr. Spring was married to his wife Blanche for more than fifty-five years. Their son Robert had lived for more than fifteen years across the street from his parents' house and had visited them virtually every day during that time. Mrs. Spring and Robert Spring had been active participants in caring for the patient's needs since the onset of his precipitous physical and mental deterioration. The burden that Mr. Spring had imposed upon his family after he developed kidney failure was cumbersome. His wife and son had to transport him three times a week to a private kidney center in another town for five hours of dialysis treatment. Furthermore, Mr. Spring's physical deterioration was accompanied by mental disorientation. His behavior at home became belligerent and destructive, and he could no longer care for himself. The crisis in the family had increased when Mrs. Spring suffered a stroke, temporarily losing her ability to speak. Robert Spring attributed the stroke to strain and exhaustion resulting from his father's behavior and condition. After some six months Mrs. Spring became well enough to be discharged from the hospital to her home.

But she could no longer take care of her husband. She needed to devote all her energies to taking care of herself.

At that time Mr. Spring was in a nursing home. His disruptive behavior was controlled through heavy sedation. Mrs. Spring and Robert Spring expressed the view that if Mr. Spring was competent to voice his opinion, he would wish to have dialysis discontinued although that would result in his death. That view did not rest on any expression of such an intention by the patient. Nevertheless, the patient's family view was accepted.

It seems that the Spring family was, indeed, a close-knit family unit. Indeed, one gets the impression that Mrs. Spring and Robert Spring loved Earl Spring. They found it terribly distressing to see the man they had shared their lives with for so many years fading away, failing to recognize them, acting brutally, and becoming a different person. They could not cope with this situation. The appeal to the court was made also in order to keep their own sanity, their own lives. It seems that Mrs. Spring and Robert Spring sincerely thought that by withholding treatment from him, they preserved his dignity. The question remains whether Mr. Spring himself would have preferred to die (Cohen-Almagor 2001, p. 126).

Thus, even if we are convinced of the family's commitment to the patient, we should not see the family's position as obligatory in all circumstances. The family's role should be held as a prominent consideration, but we should take into account first and foremost the best interests of the patient. The family is not necessarily capable of rational decision-making, and even if it is, its interests are not necessarily identical to the interests of the patient. The patient's best interests should always be first and foremost in our mind (Hardwig, 1990, 2000; Richman 1987; Jennings 1992; Kushner 2010).

## **Conclusion**

After a few days of receiving the morphine treatment, SC's elder son YC arrived for his weekly visit. He found his mother on the verge of death and enquired what had happened since he last saw her a week ago. When YC understood that she received morphine treatments, he demanded to transfer her to the near hospital. The attending physician

insisted that SC received appropriate care at the nursing home and refused to transfer the patient. YC insisted. After consultation with a senior physician, permission was granted. SC was transferred to the hospital, where the morphine regime was stopped immediately. SC's younger son, who realized that something terribly wrong was going on, arrived the following day. Both sons demanded that their mother receive healing treatment. It took 72 hours for SC's body to clear the morphine. With the appropriate treatment and counseling, SC resumed her will to live. With the right treatment, depression can be transient. Upon collecting herself, SC failed to understand why the people at the nursing home were so quick to grant her request to die. The mere mentioning of the nursing home name became traumatic to her. A few weeks later, SC underwent an operation to open blood vessels in her left leg.

This episode raises alarm bells regarding potential abuse of the Dying Patient Law as it is applied to fragile and vulnerable patients in nursing homes. This episode clearly violates the letter and the spirit of Israeli law and would be considered malpractice elsewhere as well. It is not at all clear if the social worker was aware of Israeli law and what was required of her to do. This episode also teaches us a number of lessons. First, patients may ask to die because life appears to be the worst alternative in the current situation. But the patient should state this wish *repeatedly over a period of time*. We must verify that such a request does not stem from a momentary urge, an impulse, a product of passing depression. We must also verify that the request is not the result of external influences.

Second, we need to arrive at a level of transparency at which proper safeguards for end-of-life medical care can be developed and maintained. At times, the patient's decision might be influenced by severe pain (Ruddick 1997; Teno, Weitzen, Wetle and Mor 2001; Wall 2002; Schatman 2007). In this context, the role of palliative care can be crucial and it need not lead to the patient's death. By palliative care is meant the active, comprehensive and total care of patients whose disease is not responsive to curative treatment, where maintaining that control of pain, of other symptoms, and of psychological, social, and spiritual problems, is paramount (World Health Organization 1990, p. 11). One important

safeguard should be proper documentation of the use of potentially life-shortening measures, including keeping records on the timing and doses of the drug and the physician's intention at each step. Such documentation may reduce the use of inappropriate large doses of medications to shorten the patient's life given in the guise of relieving pain and suffering (Sprung 2008, p. 13).

Ganzini and colleagues report that as a result of palliative care, some patients in Oregon changed their minds about assisted suicide (Ganzini, Nelson, Schmidt *et. al.* 2000, p. 563; Morrison and Meier 2004). The medical staff must examine whether it is possible to prevent or to ease the pain by means of medication and palliative care.<sup>9</sup> The Oregon *Death with Dignity Act* (13 Or. Rev. Stat. § 3.01, 1998) requires the attending physician to inform the patient of *all* feasible alternatives, including comfort care and pain control (Cohen-Almagor and Hartman 2001). If it is possible to prevent or to ease the patient's pain, then the patient's request to die should not be fulfilled; instead, the necessary treatment should be prescribed.

Third, coping with pain and suffering can drain all of the patient's emotional strength, exhausting the ability to deal with other issues. In cases of competent patients, the assumption is that the patient understands the meaning of the decision. A psychologist's assessment is crucial in the process. There should be attending psychologists in nursing homes and hospital wards to speak with patients, discuss their condition, assess their mental capabilities and ability to make fatal decisions at the end of life. Psychologists can confirm whether the patient is able to make a decision of such ultimate significance to the patient's life, and whether the decision is truly that of the patient, expressed consistently and of her own free will. Most importantly, the role of psychologists is of vital importance in providing comprehensive primary care for patients with multiple chronic conditions. It is worthwhile to hold several such conversations, separated by a few days. The patient's loved ones and the attending physician should be included in at least one of the conversations.

Fourth, it is reiterated that physicians should invest time in their patients. The specialization process is such that physicians see only the organ in which they specialize. Some see only the heart. Others only the liver. Yet others only the lungs. Yet others only the

kidneys. No one sees the patient as a whole, as a human being who needs to preserve hope and understand her condition. Physicians need to understand that time is a worth-while investment as physician-patient direct communication is crucial in the healing and caring process. By “direct communication” it is meant verbal communication, active listening, voice management, non-verbal communication and cultural awareness (McCullagh and Wright 2008; Tamparo and Lindh 2007). Without communication, patients are in a limbo, uncertain, afraid, not knowing what to expect, victims of their worst speculations and nightmares. On the other hand, positive communication with patients addressing all of the patient’s health-related needs and concerns can decrease patient anxieties, increase patient trust, and result in a constructive experience for all involved. The patient must be informed of the situation and the prognosis for recovery or escalation of the disease, with the suffering that it may involve. There must be a free flow of information and coordination between patients and all who provide care for the patients, including specialist physicians, rehabilitation therapists, mental health professionals, home care providers, and social workers (Boult and Wieland 2010). The communication should be two ways, where physicians not only talk but also listen to their patients. What does the patient want? Why she wants this? Listening to the narrative may reveal misconceptions or misunderstanding that can be corrected; alternatively, the narrative may affirm that the patient knows exactly what she wants because of valid reasons. Open communication is vital in the decision-making process.

Fifth, it must be ensured that the patient’s decision is not a result of familial and environmental pressures. At times, patients may feel that they constitute a burden on their loved ones. The patients’ motives should be evaluated closely so as to see to what extent they are affected by various external pressures (as opposed to a truly free will to die). A situation could exist in which the patient is under no such pressure, but still does not wish to be a burden on others. Obviously, we cannot say that the feelings of patients toward their loved ones are not relevant to the decision-making process (Cohen-Almagor 1996; Hardwig 2005; Casarett 2010).

Sixth, the decision-making process should include a second opinion in order to verify the

diagnosis and minimize the chances of misdiagnosis, as well as to allow the discovery of other medical options. A specialist, who is not dependent on the first doctor, either professionally or otherwise, should provide the second opinion. Furthermore, the consulting physician must verify that the patient is capable, is acting voluntarily, and has made an informed decision.

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<sup>2</sup> The Dying Patient Law, Chapter C, Section 4 (December 15, 2005). My research conducted in six countries and in more than thirty hospitals and research centers showed that the vast majority of patients cling to life, no matter what. Even in the most miserable conditions, patients opt to live. See Cohen-Almagor (2001, 2004).

<sup>3</sup> PCU is also termed PVS, Persistent Vegetative State. I object to this term on ethical grounds. I do not believe this term serves the patient's best interests. See Cohen-Almagor (2000A); Bedell, Graboys, Bedell and Lown (2004).

<sup>4</sup> See also Sykes and Thorns (2003); Sheldon (2009); Editorial (2008); Sprung *et al.* (2008). In his comments, Shimon Glick wrote: "I think the double effect is fine, but it is often misused and abused by dishonest application."

<sup>5</sup> No doubt that some social workers in Israel can provide counseling. Charles Sprung notes in his comments that in his experience some of them are excellent. This was not the case here.

<sup>6</sup> May I emphasize that my critique refers only to that specific social worker, and not to all social workers. In her comments, Pery wrote that my critic might open the way for negative critic of social work as a profession. I certainly do not wish to do that.

<sup>7</sup> Sprung wrote in his comments: "I don't think it is that uncommon and certainly a problem."

<sup>8</sup> Sprung commented: "We have noticed that sometimes a DNR order becomes Do Not Care order, with the medical and nursing staff spending less time on rounds discussing or even caring for the patient. With so much medical uncertainty, it is fair to communicate to a patient the half full cup rather than the half empty cup." For further discussion, see Cohen-Almagor (2000A); Derse (2000) and Cohen-Almagor (2000B).

<sup>9</sup> Directive 7 in *The General Manager Circular*, Israel Ministry of Health, no. 2/96 (January 31, 1996) holds: "Doctors must concentrate their efforts on easing the pain, torment, and suffering of the patient, a subject of highest priority in medical treatment, especially when terminal patients are concerned," p. 12 (Hebrew). For further deliberation on pain control mechanisms and their importance, see Quill, Lo,

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and Brock (1997); Doyle, Hanks and MacDonald (1998); Quill, Coombs-Lee and Nunn (2000); Jost and Mendelson (2003); Morrison and Meier (2004).