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DESIRES IN PALLIATIVE MEDICINE. FIVE MODELS OF THE
PHYSICIAN-PATIENT INTERACTION ON PALLIATIVE
TREATMENTS RELATED TO HELLENISTIC THERAPIES OF
DESIRE

ABSTRACT. In this paper, we explore the desires that play a role at the palliative stage and relate them to various approaches to patient autonomy. What attitude can physicians and other caregivers take to the desires of patients at the palliative stage? We examine this question by introducing five physicians who are consulted by Jackie, an imaginary patient with metastatic lung carcinoma. By combining the models of the physician-patient relationship developed by Emanuel and Emanuel (1992) and the Hellenistic approaches to desires analyzed by Nussbaum (1994), five different ways of dealing with desires in the context of palliative care are sketched. The story of Jackie shows that desires are to a certain extent responsive to reasoning. In the palliative process, that can be a reason to devote attention to the desires of patients and caregivers and to determine which desires need to be fulfilled, which are less important, and how they are linked to emotions the patient has.

KEY WORDS: autonomy, desires, Nussbaum, palliative medicine, physician-patient relationship

INTRODUCTION

Autonomy is a highly valued notion in palliative care. Despite the moral significance attributed to the concept, autonomy frequently operates as a vague, ambiguous or elusive concept (Secker, 1999, p. 44). One of the unclear aspects pertains to the position of emotions and desires in the concept of autonomy. In bio-ethics the emphasis is on rationality; an autonomous patient is expected to make decisions and act on the grounds of reasonable arguments and not on the grounds of emotions, intuitions or desires. At the palliative stage, when care is not focused upon combating disease but upon the patient's general well-being, it is, however, of particular importance to make a connection with the patient's deepest desires and needs and with his sense of what is important.

In this paper, we explore the desires that play a role at the palliative stage and relate them to various approaches to patient autonomy. By combining the models of the physician-patient relationship developed by Emanuel and Emanuel (1992) and the Hellenistic approaches to desires analyzed by



Nussbaum (1994), we will sketch five different ways of dealing with desires in the context of palliative care. The first model is paternalistic/Epicurean. It emphasizes the role of trust between physician and patient and the need to liberate the patient from anxieties. The second model is the informative model, which focuses on the freedom of the patient to make his own decisions. The third is the Skeptic model, which aims to bring about detachment on the part of the patient. The fourth is the interpretive/Stoic model. It stresses the need to clarify the patient's desires. The last is the deliberative/Aristotelian model, which aims to develop desires through learning and communication.

We will present the five models by introducing five physicians,¹ who are in turn consulted by Jackie, an imaginary patient with metastatic lung carcinoma.² Accompanied by her only daughter, Louise, she will consult five physicians who each respond to her in a different way. Although it is not always clear to her exactly what her desires are and although they change and are sometimes contradictory, to a certain extent she will turn out to be responsive to reasoning. In the palliative process, that can be a reason to devote attention to the desires of patients and caregivers and to determine which desires need to be fulfilled, which are less important, and how they are linked to the emotions the patient has. Before we turn to the five models, we will briefly discuss the concept of desire, and its relation to emotion and belief.

DESIRE, EMOTION AND BELIEF

Desires motivate people to do or not to do certain things. A desire for food motivates a person to prepare a meal and eat it, and a desire for peace and quiet stimulates a person to look for a tranquil spot. Desires indicate what we think is worthwhile, what we want or would like or demand. Desires can be classified as first-order and second-order desires (Frankfurt, 1971, p. 7). First-order desires pertain to something specific like a cup of coffee. Second-order desires are desires to have or not to have certain first-order desires. The idea that it is late at night and drinking coffee can keep you

¹The use of the term physician-patient relationship implies that our attention is focused on medical decision-making processes and the physicians' responsibilities in these, although other caregivers (nurses, relatives, psychologists or pastoral workers) may have similar relations and responsibilities to the patient.

²The story of Jackie is a compilation of stories of and from patients traced from medical and autobiographical literature.

up might make a person decide not to give in to the desire for a cup of coffee. First-order desires are easy to identify at the palliative stage, i.e. the desire for good care, security, safety, monitoring, not to have to suffer and not to die lonely. Because of our interest in autonomy, it is important to note that the desire for decision-making authority is also a first-order desire that people appreciate and want (second order) because it is a means towards other desires (White, 1994, p. 131). The desire to be a good caregiver and provide the patient with good care is a first-order desire. How a person feels about this desire and what he wants to do about it is the second order. Second-order desires imply a capacity to reflect on one's desires and wishes and to revise them. They are related to what a person deems important and worthwhile in life.

Desires are linked to emotions. Positive emotions such as contentment, happiness or enthusiasm can result from the fulfillment of desires. Negative emotions such as depression or frustration result from desires not being fulfilled. They can also result from a conflict between first-order desires. If a terminal patient wants to continue to have a clear mind up until the end, she can get depressed if her wish conflicts with the desire not to experience pain.

Second-order desires are linked to beliefs; the belief that someone is going to die soon makes them desire certain things more than before or makes them more aware of certain desires. Specific conditions also influence the emergence of these desires. Technical or medical possibilities for lengthening a person's life and alleviating their pain can influence the desire to give in to the wish to live as long as possible and try every available treatment to attain this goal. Legal procedures for euthanasia, as exist for instance in the Netherlands, may influence the desire for a 'mild death'.³

What attitude can physicians and other caregivers take to the desires of patients at the palliative stage? We examine this question by following Jackie, who is diagnosed with lung cancer a few months ago.

THE PATERNALISTIC/EPICUREAN MODEL

In palliative care, caregivers have to constantly balance beneficence and respect for patient autonomy. In the paternalistic model, the beneficence prevails, and the physician tries to provide the care that is most beneficial to the patient's well-being. The model assumes that there are shared ob-

³The desire for a hastened death is not dealt with as a special case, but seen as one of the desires that patients may have in the palliative stage.

jective criteria for determining what is best (Emanuel and Emanuel, 1992). Quill and Body, both experienced in working with the dying, state:

One of our goals in working with the dying is to help them try to achieve a 'good death'. The meaning of this idealized concept may be highly individual, but there are likely to be some common objectives. The first is to die in relative physical comfort, both out of pain and in a clear state of mind. A second objective is to die supported by and connected to important persons in one's life (Quill and Brody, 1995, p. 1250).

Based upon these shared objectives, which have been described in numerous articles, guidelines and policy papers on palliative care (World Health Organization, 1989; American Society of Clinical Oncology, 1998) and upon his own experience with other dying patients, the physician often knows better than the patient what is good for him. The physician is the one responsible for the patient dying a good death, i.e. in such a way that he does not suffer unnecessary pain, feel humiliated or die in total loneliness or despair.

When Jackie visits a physician who acts in a paternalist way, he tells her that curative treatment is no longer possible. He promises her he will do all he can to please her and never abandon her. When she consults this same physician a few months later because she is coughing blood, he tells her he can alleviate the symptoms quite simply by way of palliative radiation. He has already made an appointment for her with the radiation therapist so she won't have to wait. Trusting him completely, she undergoes the treatment, which does indeed make the symptoms disappear. The symptoms come back two years later, and once again palliative radiation is effective.

It is another couple of years before the physician sees Jackie again. She has lost weight and is short-winded. The tumor has grown quite a bit. Although Jackie has known for some time that she is dying, in the hospital she is suddenly prone to severe anxiety. She does not share this feeling, but the physician soon concludes from her stories that she is very frightened. He interprets her emotions as a fear of dying. He is aware that there is a deeply rooted fear of death in our society and that it is consequently important to convince Jackie this fear is based upon an erroneous conception of dying. In a certain sense, the physician bears a resemblance to an Epicurean teacher. As Nussbaum argues,

Epicurus' challenge . . . is always to get the pupil to see that what he delivers to her does in fact fulfill her desires, at least the deepest and most central ones. She may in the process alter her ideas concerning what her desires are, and which of them

are deepest; but in the end the therapist must make the connection (Nussbaum, 1994, p. 122).

The physician explains to Jackie that dying means breaking the ties with her loved ones and with everything she values in life. It is his belief that detachment is needed to prepare for dying and to imagine one's own death. As with the Epicurean pupil, the paternalistic physician expects the patient to accept his truth and put her fate in his hands. If she would stay with this physician, the time Jackie enters the dying stage, she will rely on the physician so completely that she will ask him to say to her "It's all right – you can go. You said goodbye to whoever you wanted to say goodbye to. You've done all you can. And we want you to have an easy time of it. So let go" (quoted from Mrs. L. in: Foley, 1999, p. 1938).

In the paternalistic model, the conception of patient autonomy is "patient assent to the physician's determination of what is best" (Emanuel and Emanuel, 1992, p. 2221). Instead of asking what the patient desires, the physician pays attention to what is not immediately transparent. He observes physically, how she behaves, and what she tells him.

With regard to desires, the focus in this model is not on the satisfaction of the patient's actual desires, but on the satisfaction of those desires that the agent would have in what Murphy calls a 'hypothetical desire situation': a patient's good is what he would desire in a setting optimal for desiring (Murphy, 1999, p. 247). The 'shared objective criteria' for dying well are supposed to be the desires each person would have if he were in an optimal situation for desiring, a situation which has not much in common with the vulnerable situation most dying patients are in. As an Epicurean, the physician knows desires often are unconscious. False beliefs on dying, shaped by images of dying persons on TV and in films, are hidden in the patient's psyche. They give rise to anxieties and feelings of uncertainty, and to desires which do not contribute to the patient's well-being. He convinces the patient that giving in to his truths will deliver her the fulfillment of her deepest desires.

However, the paternalistic/Epicurean approach can also evoke resistance on the part of the patient. What if Jackie does not completely accept the communal aims? What if the Epicurean approach to death goes against everything Jackie has always thought about life? She will soon adopt a stance of opposition to the physician's methods. If this is how Jackie reacts, it would not surprise us if she looked for a physician who attaches less significance to general ideas about a good death and gives more significance to the autonomy of the patient, a physician who works according to the informative model.

THE INFORMATIVE MODEL

The second model is the informative, informed consent or consumer model. In this model the physician provides the patient with all the relevant information, the patient chooses from the various treatment options, and the physician carries out the interventions the patient has chosen. This is the dominant model in bio-ethics and health law and is in keeping with the preferences of many patients about decision making. Many present-day physicians adhere to this model, especially since patients who are involved in the decision making are more often satisfied with the care and accept the treatment better (Deber, 1994, p. 173).

The informative model asserts that the field of medicine should make itself available to every human being. The focus of the model is on meeting the desires of the consumers. The model assumes there is a clear difference between facts and values or between facts and desires. The physician should present all the available facts, and it is the values and desires of the patient that determine which treatment should be given. The patient's desires should not be made the object of debate between physician and patient. In this model the physician is "a purveyor of technical expertise, providing the patient with the means to exercise control" (Emanuel and Emanuel, 1992, p. 2221). This model does not confine itself to the curative stage. It can also include the palliative stage because patients want to have a say and have control over everyday decisions about care at that stage as well (Borttoff et al., 1998).

The first time Jackie consults the informative physician, he tells her in all honesty that she has small-cell lung cancer, and that the tumor is inoperable because the risks would outweigh the possible advantages of removing it. The prognosis of this kind of cancer is extremely poor. He tells her about the options that are feasible at the moment, i.e. radiation, chemotherapy, or neither of the two and waiting to see what happens. Each option has advantages, side effects and disadvantages. He asks whether she understands the information and if so, whether she can tell him exactly what she has understood. Jackie, who worked as an accountant before she retired, quickly reproduces the information the physician has provided. The physician tells her she can take some time to think about it, but she says she does not need any more time. She has come well prepared for this talk with the physician, she is familiar with the alternatives the physician has mentioned, and she has decided not to undergo any treatment. She chooses quality rather than quantity, she firmly states. The physician has respect for Jackie's choice and admires the clear and unequivocal way she formulates what is important to her and why she wants to wait and see.

The impression her unhesitating response made on him is one reason why, when she comes back later and tells him she is coughing blood, he not only presents her with the possibility of palliative radiation, he also asks her to play a role in deciding how much radiation she wants to be given (see Amols et al., 1997 on how this idea is put into effect). Jackie is fascinated by this idea. She and her daughter spend a whole evening figuring out the balance she wants between the advantage (a reduction in the size of the tumor) and the disadvantage (damage to the tissue around the tumor) of radiation. They decide to go for a relatively large dose of radiation. Jackie had not expected to live this long anyway, and the luck she has had so far makes her decide to go ahead and take a chance. She calls the physician and he arranges an appointment for her. Jackie is very satisfied with how this whole process has gone. And in the end, the radiation quickly makes all her complaints disappear and reduces the size of the tumor.

In the informative model, patient autonomy is conceived of as patient control over medical decision making. The physician provides the factual information, but feels that the interpretation and evaluation of this information in light of the patient's values and desires is a matter that does not concern him. He only questions the choices patients make if and when he doubts their competence, their comprehension of the information, or the voluntary nature of their decision.

In accordance with this line of thought, the physician in the informative model conceives of desires as the patient's actual desires. Patients' actual preferences are taken seriously, and not overridden by general desires of beneficence or discussed because of deviating from general ideas on dying well. The physician's job is limited to listing the patients' desires. When the patient himself lacks the capacity to express his desires, a close relative or other surrogate decision-maker is asked to speak for the patient (Slomka, 1995, p. 542). Only when the patient's current desires are based on false beliefs, i.e. false facts on the treatment options, diagnosis or prognosis, or when they are illicit or 'abnormal' the physician will discuss the patient's desires.⁴

⁴The model is in accordance with the so-called desire satisfaction theory which asserts that the good for persons is the satisfaction of their desires or preferences. White (1994, pp. 41–42) discerns two theoretical problems of this model. The first is that some people have immoral, illicit preferences like those that are racist, sexist or "perverted", of which most people think they should not be honored. The second problem is that some people develop 'abnormal' or 'abnormally acquired' desires of which the physician feels they are suspect in view of their origin. Like a death wish that originates from the patient's fear of being a burden for his relatives.

Although many patients will be happy with his approach, others might feel his attitude is lacking in compassion, empathy or care. When Jackie visits the informative physician again at the terminal stage, there is not much left of her resolute determination. She feels physically and mentally vulnerable. The physician does all he can to nonetheless involve her in the decision making, but Jackie is totally indifferent. She experiences the responsibility the physician puts on her shoulders as a burden. She just wants peace and quiet. Louise decides to look for a more relaxed physician. This physician is a skeptic.

THE SKEPTIC MODEL

In the Skeptic model, the aim of the physician-patient interaction is to bring about a state in which the patient does desire nothing but peace, detachment and freedom of disturbance. Living and dying well can be reached when human beings free themselves from all beliefs and commitments. One of the beliefs people have to get rid off is the belief that pain and suffering are evils to be avoided. The skeptic physician knows that the patient's encounter with bodily pain and suffering can be a source of anxiety that spoils a carefree life. Whereas the effort of the paternalistic physician is to force nature around to the human demand for a pain and symptom free death, the Skeptic physician thinks this does not make sense, because that effort brings about more pain and anxiety than it alleviates. Instead of conceiving pain as an evil to be avoided, the Skeptic physician states the element of belief, i.e. that pain is bad, intensifies the patient's agony. Take away this belief and the patient is no longer in distress. The Skeptic cure for distress is the purgation of all cognitive commitment, all belief, from human life.

Disturbance and distress are diseases of reason which can be cured by argument. Skeptism, as reported by Sextus, is:

“an ability [*dunamis*] to set up an opposition of appearances and thoughts, in any way at all, an ability from which we come, through the equal force [*isostheneia*] of the opposing arguments and states of affairs, first into suspension [*epoche*], and after that into freedom from disturbance [*ataraxia*]” (Sextus quoted by Nussbaum, 1994, p. 285).

Like the contemporary postmodernist, the Skeptic physician does not cling to any definite belief or ultimate truth. He is anti-dogmatic in every aspect of life, his own job, palliative medicine, included. The reading as a student of Illich's *Medical Nemesis – The Expropriation of Health* (1975) has learnt him to be skeptic towards so-called medical progress. He thinks

dogmatic physicians – who have definite beliefs on the efficiency and efficacy of medical treatments – cannot really cure diseases because they create new diseases in place of the old.

Jackie meets the Skeptic physician when she is in the transition of the curative to the palliative stage. After he has informed her on the palliative treatment options, the physician tells her he likes to know whether there is anything that frightens her or makes her feel uncomfortable. Jackie tells him she is harassed by the question “Why me?”. She is only 68, has always had a healthy lifestyle, and she has still so many dreams to come true. Besides that, she is anguished by her prospects. How much time will she get? She would not mind to live a little longer. If only to enjoy next spring, or maybe next summer. The physician opposes to her argument the argument that life has only value in living it. The end of human life is just life, and is not to be found in an imaginary future. You have to live it in the way it goes. Human life is mortal, and she is part of that mortality. The cycle of life means that her death and that of others give room for a new generation. Instead of asking “Why me?” she could ask, with equal strength “Why not me?”. In opposing her arguments, the physician tries to bring Jackie in a state of equipoise in which she recognizes that to all her beliefs other beliefs of equal strength are opposed. In time, the arguments and counter-arguments are scrutinized again and again. In the end Jackie does not have any belief important enough to defend. She reaches a suspension, and after that a freedom of all disturbances. Her Skeptic attitude makes that Jackie is no longer troubled by the uncertainty that bothers most patients who try to keep control and reach a balance in spite of the deteriorating conditions and the unknowns related to the timing of their death (Ronson et al., 1998, p. 38).

The conception of patient autonomy in this model is the patient’s ability to set up an opposition of appearances and thoughts. There are no definite truths, no authorities who may guide or motivate the patient. His autonomy is constituted by his bodily feelings, experiences and desires, and not by his beliefs, biography, or respect for better alternatives.

Eliminating all beliefs and goals is only possible when patients desire for and assent to the Skeptic end of tranquility. In the end, the patient has no other desire than the desire to be happy with what is happening to him. Leaving behind all beliefs and pursuits, he desires a life free from disturbance, that is the Skeptic way of human flourishing.

When Jackie’s disease is becoming terminal, she enters the nursing home where the Skeptic physician works. She has reached a state of indifference. Within a few days, she dies. Although Jackie appeared satisfied with the Skeptic approach, Louise is not. Why did the physician prefer a peaceful

and undisturbed way of dying to a death agony in which the patient struggles to stay alive to the end? Louise wonders if the Skeptic physician does recognize the power of the emotions related to death:

No matter how death is described, what words are used, it has the power to cause emotional disturbance. We are always touched. . . . Death never comes with indifference. On the contrary, thanks to death, our awareness of it makes us human, differentiating us from other species (Montigny, 1998, p. 8).

In medical literature, the idea that the emotions related to death are not to be escaped is common and probably the reason that in medical literature the Skeptic physician does not appear on stage. Most caregivers in palliative care, however, know that they cannot do their job when they feel with each dying patient the disturbing emotions described by Montigny. Many of them have already difficulties dealing with the emotional distress involved in palliative care (Wakefield et al., 1993). Some skepticism can be useful to be able to care for the dying for a longer period. Too much skepticism, however, alienates the physician from the patient and his process of dying. For the sake of the argument, we bring Jackie back to life which gives Louise the opportunity to look for a physician who does care for the things she and her mother consider important in life.

THE INTERPRETIVE/STOIC MODEL

In the interpretive model, the aim of physician-patient interaction is to clarify what the values and desires of the patient are and how they can best be satisfied. In their outline, Emanuel and Emanuel say: "the physician works with the patient to reconstruct the patient's goals and aspirations, commitments and character. At the extreme, the physician must conceive the patient's life as a narrative whole, and from this specify the patient's values and their priority" (Emanuel and Emanuel, 1992, p. 2222). The presumption of the interpretive model is that human beings are able to know and understand their first-order desires, and that they have second-order desires to decide which desires should have priority.

The interpretive procedure used by the physician is similar to the procedure in Stoic desire therapy as described by Nussbaum, although the aim of the therapy is rather different. Both models attribute a high value to the faculty of reason as the faculty of choice. Both combine a respect for reason with a critical examination of individual beliefs, emotions and desires. However, whereas the Stoic emphasis is on the extirpation of all desires, emotions and passions, the focus of the physician-patient interaction in the

interpretive model is to elucidate desires and reach a coherent ordering of the patient's life, his desires and the situation he is in. The interpretive physician does not aim at the Stoic removal of the passions, but at the recognition, understanding and valuing of the patient's desires.

Like the job of the philosophical teacher, the job of the interpretive physician is manifold, complex and personal. As Nussbaum states,

The (Stoic) teacher's job requires subtle psychological interaction at a deep level, which grapples with whatever memories, wishes, fears, and habits influence the pupil, constructing the ways she sees the world. . . . The teacher is a doctor — but a doctor who leads the patient in an exacting exploration of her own insides (Nussbaum, 1994, p. 328).

When Jackie meets the interpretive physician, her strongest desire is to control the disease and her life. Having cancer feels like being betrayed by herself, by the cells of her own body (Stacey, 1997, p. 177). Although she now knows, after meeting the Skeptic physician, that there is no best remedy in cancer care, she would appreciate getting help in finding out what is worth valuing and what is not. The first time she consults the interpretive physician, he informs her of what her alternatives are. He asks if she has an idea which one would suit her best. Jackie replies that as a feminist, she has decided long ago to care for herself. She wants to stay independent of external support as long as possible. Her main goal is thus to avoid chemotherapy and radiation, and strengthen the belief in her own capacity to fight the cancer. The physician respects her choice on medical grounds. There is not much chance that chemotherapy or radiation would do her any good, and in his opinion it does not make sense to discuss her desires and values.

When Jackie consults the interpretive physician a few months later because she is coughing blood, she once again expresses the desire to keep control and not submit to chemotherapy or radiation. This time, however, the physician is not convinced she is choosing the alternative that best suits her desires and values. What values is Jackie referring to when she talks about her capacity to fight the disease, caring for herself, and keeping control? Jackie tells him she feels frustrated about coughing blood. It means she has not been strong enough to fight the cancer. She also feels bad that she has to call upon her daughter more and more often. The physician carefully works through Jackie's arguments, emotions, desires and values with her. Together they come to the conclusion that a short course of radiation would be the best alternative. There is a good chance she will stop coughing blood, and not coughing blood can give Jackie a new sense of control. We know from her visit to the paternalistic physician that Jackie was bet-

ter after the radiation. The difference in decision-making between the paternalistic and the interpretive model is that in the former one, it is the physician who decides based on shared objective criteria that radiation is the best treatment option. In the latter one, it is the patient who decides which desires have priority and which treatment or care best suits them. Like the Stoic teacher, the interpretive physician feels that once the patient has determined what is desirable and what is not, she will feel “that even the most painful and confusing aspects of life would be made more tolerable by understanding and by choice, by the sense that she herself has drawn the boundary of here and not here, had formed her desires and evaluations in this way and not in this” (Nussbaum, 1994, p. 320). In contrast to the paternalistic physician who accepts that many patients prefer to be passive at the palliative stage (as is clear in the survey studies by Degner and Sloan, 1992), the interpretive physician is suspicious of passivity. He wants to know whether the passivity is in keeping with what the patient desires and values, and is not the result of being unable to voice one’s desires. He always expects his patients not to be simply patients, but to be their own doctors as well. Patient autonomy in the interpretive model is an autonomy to be developed by interpretation. Patients not only have a right to choose from the available medical alternatives and options for care, they are also empowered to choose and determine who they are, what they value and desire, and what they think is necessary for living and dying well. In the physician-patient interaction, people are enabled and encouraged to develop autonomy.

In the interpretive model, desires are subjected to conversation, in order to be clarified. The physician is convinced that in order to give patients a real say in the palliative phase it is necessary to clarify the patient’s desires and to be responsive to them. Whereas the paternalistic and the Skeptic physician start from what they think is best for the patient, the interpretive physician’s first interest is in hearing the patient’s voice, his wants, desires, reasons, beliefs and emotions. And he does not stop short after informing the patient, like the informative physician. In his opinion, the patient’s desires and wants can not be separated from the facts.

Although Jackie is very content with the physician’s approach, in the course of time she notices that the physician is not always able to stand by his principles. She feels that she needs someone who is less easy in accepting what she brings up, someone who takes a stance himself and motivates her to examine her own priorities more critically. Therefore she asks her daughter to make an appointment with yet another physician, who works according to the deliberative/Aristotelian model.

THE DELIBERATIVE/ARISTOTELIAN MODEL

The last model which Emanuel and Emanuel (1992) describe is the deliberative model. As in the interpretive model, the aim of the physician-patient interaction is to find out what the patient desires and values. In the deliberative model, however, the physician does not stop once the desires of the patient are clear. Adopting the attitude of a teacher who knows certain desires are worth more to the patient than others, he discusses the patient's desires. The model presumes that desires and values are responsive to deliberation and reasoning, and by appealing to second-order desires, patients can alter their desires.

The deliberative model has a great deal in common with the Aristotelian approach to desires, as described by Nussbaum. Aristotle's method addresses the desires the person has, insists on a critical scrutiny of them, is critical of popular views, propagates a rigorous scrutiny of what the individual experiences, and aims at reaching a consistent truth that is responsive to the particular situation and corresponds with the deepest human beliefs and desires. The aim is to elucidate the individual's desires and reach a mutual agreement concerning the 'truth' and suitability of these desires. The judgment on the desires is reached in the pursuit of truth, recognizing that truth is always constrained by what we can do, what we are and what we desire. The judgments on desires are formed by consulting what Aristotle calls 'reflective desires':

Such thought experiments involve complex imaginative and comparative activity; the desires they elicit and consult are not brute or untrained, but heavily shaped by argument and deliberation (Nussbaum, 1994, p. 63).

In this reflection, which seems to be similar with the reflective capacity implied in the idea of 'second-order desires', special attention is devoted to emotions, since emotions are linked to desires. The individual is asked to distinguish correct from incorrect emotions, to alter the latter and thereby alter his desires.

Like the informative and the interpretive physician, the deliberative physician starts by informing Jackie about the medical treatment options and asking for her opinion. Again, Jackie tells that as a feminist, she wants to keep control, rely on her will power to fight the disease and care for herself. In contrast to the interpretive physician who seeks to find out which alternatives best suit her wish to maintain control, the deliberative physician does not accept her desires as such. He tells her he knows feminism has been very critical about medicine because it objectifies the female body,

and transforms women into passive objects. But does Jackie know there are tendencies in medicine, oncology included, to work in a more patient-centered fashion? Physicians have learnt and are learning to inform their patients, not only to discuss biomedical but also psychosocial issues, and to involve them as much as possible in the decision-making process (Siminoff, 1992; Ford et al., 1996; Fallowfield et al., 1998). Furthermore, isn't the idea of control a very masculine one with the mind controlling the body? Isn't the self self-health is referring to an overly individualized self? And what about the emotions, are they allowed to have a place in this story of control and mastery (Stacey, 1997, pp. 196–200)? Like Aristotle, the physician thinks the “best human life is a life rich in attachments to people and things outside the self . . . a life rich in possibilities for emotions such as love, grief, fear and even anger” (Nussbaum, 1994, p. 42). He tries to persuade Jackie to detach herself from the desire to be a heroine fighting cancer. To reach this goal, he not only presents his own arguments, he also explores and scrutinizes her feelings. What is she anxious about in connection with giving up control? Jackie tells him she is afraid that if she stops fighting, she will soon be dead. Jackie is not immediately convinced. Once returned home, she tries to imagine what it would mean if she would give up the idea of control. After talking with Louise, who tells her she enjoys caring for her, she accepts the truth expressed by the physician and alters her desires. When she reaches the terminal stage, she is glad the physician discussed her desires. In contrast to an earlier stage, it now appears quite natural to her to be cared for and surrender to the process of dying. She dies quietly.

In the deliberative model, patient autonomy implies moral self-development: “Autonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize the values. The process of deliberation integral to the deliberative model is essential for realizing patient autonomy in this way” (Emanuel and Emanuel, 1992, p. 2225).

The deliberative physician thinks it is important to discuss desires critically. Whereas the interpretive physician does not feel it is his task to discuss desires – even if they are based on false beliefs – the deliberative physician always starts a dialogue on the content of the patients desires and what he thinks is desirable for the patient. If he is convinced the patient's desires do not serve his well-being, he will convince the patient to transform his desires. A disadvantage of the deliberative model, though not experienced by Jackie, is that if physicians do not have the skills necessary, they may unwittingly impose their own values on their patients.

The model may “metamorphose into unintended paternalism” (Emanuel and Emanuel, 1992, p. 2225). Besides that, for patients who are in pain and feel miserable the reasoning of the deliberative physician can be a source of distress. A little passivity, as allowed by the paternalistic physician, could be very welcome to them (Degner and Sloan, 1992).

CONCLUSION

In palliative care, the physician is first of all a doctor of human life. Curative treatment is no longer possible, and the aim of the physician-patient relationship shifts to “the achievement of the best quality of life for patients and their families” (WHO, 1989). The whole point of palliative care is human well-being, or in Nussbaum’s words, “human flourishing”. What does human well-being or human flourishing at the end of life mean? Should we rely on ‘shared objective criteria’ of what it is to die well? Should we respect each patient’s desires and preferences as truths not to be discussed? Should we steer a middle course between objective and subjective criteria for living and dying well, and find ways to discuss general ideas and connect them with personal beliefs and desires? Should we discuss all truths, and not accept any individual or shared definite belief?

To deal with these questions, we would need to get clear about what human well-being and what dying well is, what role desires, emotions and needs play in the process of dying, what the role of reasoning is in the physician-patient interaction and whether this relationship should be based on shared objective criteria, compassion, general medical knowledge on ‘quality of life’, consumers’ preferences and desires, the physician’s attention and understanding of the patient, or mutual understanding and dialogue. Should the physician be a father, purveyor of technical expertise, partner, a skeptic person, advisor, friend, or teacher? We do not think it is possible to find general answers to these questions. As shown in the story of Jackie, what is right depends on who the patient is, what she wishes, feels and beliefs, which stage of the disease she is in, how strongly she is attached to relatives and external goods, and what relationship the physician has with her. None of the models suits all desires of all patients in all situations.

In the paternalist/Epicurean model, the emphasis is on general human desires in the context of the dying process. If the patient currently has different desires, these should be altered or excluded. In the informative model, patient’s actual individual desires are central. The physician has to make sure that these desires are being met. Only in case the desires are

clearly dangerous and irrational, the physician may overrule them, and take recurs to paternalism. The skeptic model does not take actual desires of the patient for granted. It rather aims to achieve a situation of detachment and acceptance. In the interpretive and deliberative model, desires are attributed a central place. These models appear to suit best the plurality and sometimes incompatibility of desires, and their relation to beliefs and emotions. They incite the patient to use the critical function of second-order desires to decide which desires have priority in achieving a 'human flourishing' at the palliative stage. Once the physician starts to accept the patient's desires as a given, either in their actual form as in the informative model or not as in the paternalistic and Skeptic model, it is difficult to return to a discourse in which desires are to be clarified and critically scrutinized. The other way around is much more easy: Once the physician notices the patient is not able or does not want to talk about his desires, he always can return to an informative, paternalistic or Skeptic model.

In the five models presented, the physicians use philosophical notions to respond in a compassionate way to the needs, wishes and desires of patients. Like the Hellenistic schools, modern medical curricula should pay more and more attention to questions of need and motivation, and to the attitude and communicative skills of the physician. A therapy which focuses on desires enables physicians, patients and their relatives to critically scrutinize the alternatives to reach a human flourishing at the end of life.

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