August 2003

The Role of Responsibility in Gynecological Oncology

Elio Sgreccia

Maria Luisa Di Pietro

Follow this and additional works at: http://epublications.marquette.edu/lnq

Recommended Citation
Available at: http://epublications.marquette.edu/lnq/vol70/iss3/2
The Role of Responsibility in Gynecological Oncology

by

Msgr. Elio Sgreccia and Prof. Maria Luisa Di Pietro

Msgr. Sgreccia is Director of and Prof. Di Pietro is Senior Researcher at the Institute of Bioethics, School of Medicine, Catholic University of Sacred Heart, Rome. Both are professors of bioethics.

The diagnostic and therapeutic approach to the patient is always charged with responsibility and tension for the physician and with expectations and fear for the patient. This is experienced in a more difficult and painful way when the patient has a neoplastic pathology of the gynecological sphere. There is the fear of having cancer and the uncertainty of the outcome of the therapy. There is also the pain of undergoing a mutilation of organs considered fundamental for the structure and recognition of one’s female identity, with the consequent incapacity to procreate or other difficulties if the woman is pregnant.

In these cases, one asks the physician to use not only his scientific competence, but also his humanity, so the patient can deal with this sad experience. Also in these cases, as in the whole practice of medicine, the physician and the patient cannot ignore that the decisions regarding clinical management involve fundamental ethical values regarding the human person, her life and her health.

If we analyze the bioethical literature on the subject, we find that the solution to difficult or conflicting situations which arise in clinical practice is often looked for with reference to principlism and, in particular, to the principles of respect for autonomy and of beneficence.1 In other words, the physician-patient relationship is reduced to two opposing sides. On one hand is the physician who, with his scientific knowledge, is able to identify the most useful strategies of intervention for the woman. On the other hand is the patient, with her expectations and convictions, but above all, with the right to choose the path that she believes most suitable.
In this context, the physician would act on the basis of the principle of beneficence, and would not only commit himself to not harming the patient (the principle of non-maleficence), but would also aim for the greatest good for her. The clinical choice is thus the result of the balance between possible risks and the expected benefits. However, one must also take into consideration the choice made by the patient, who would act on the basis of respect for her autonomy (recognition of moral autonomy, self-determination, freedom of conscience), which then becomes concrete in the obligation of informed consent. Therefore, for the patient there are obligations based on the principle of autonomy, whereas the physician intervenes by virtue of the principle of beneficence.

At first glance, referring to the above-mentioned principles may appear to be of great help in clinical practice. In reality, these principles are often in conflict with each other and make it difficult to answer the question “What should I do?” For example, if a woman, acting under the principle of autonomy, decided to refuse necessary therapy, a physician would not be able to act under the principle of beneficence to save her life. The presence of this conflict should not surprise: it is the logical consequence of the lack of a foundation of the principles themselves or, to be more precise, of the presence of a double and contrasting foundation, which is utilitarian on one hand (What is useful to do?) and deontological on the other hand (What should I do?).

The conflict inherent in principlism is even more obvious when the clinical dilemmas concern not only the woman-physician dyad, but rather the woman-fetus-physician triad. Which principle should oblige the mother and the physician to act in the interest of the fetus?

Certainly not the principle of autonomy, since the fetus has not yet acquired the capacity to make decisions and to exercise his freedom; but not even, it is said, the principle of beneficence unless the fetus can be considered a “patient”. And when can a fetus be considered a patient?

Only when, one reads in Cervenak and McCullough’s paper, “the fetus has a good chance of becoming a child”, or rather when it is in a viable phase (at least 24 weeks of gestation). Consequently one denies that the fetus may have subjective rights in any phase of his development and in any condition: if, in fact, the fetus is not yet viable, it is the mother who decides whether he should be considered a patient or not; if, however, the fetus is already viable, the clinical decision, whether or not shared by the mother, is to be taken by the physician in the interest of the fetus.

From what has been said, it is clear that there are some gaps in the appeal to principlism: in the name of autonomy one ignores the source it proceeds from, that is the life that is its fundamental condition; in the name of beneficence one ignores the good of the patient. In order to resolve this conflict, to respect the fundamental rights (to life and the protection of
health) of all those involved, it is therefore necessary to think more deeply and revisit the meaning of the terms “autonomy” and “good”. 

First of all, in medicine the exercise of autonomy is not a monologue but a dialogue. The autonomy of the patient “talks” to the autonomy of the physician. The “subject” of the conversation is the good of the patient and, if present, of the fetus, a good that unites them and that also has to overcome any personal interest. Moreover, what should one mean by “good”? According to Pellegrino and Thomasma, the “good” should include: the biomedical good; the concept that the patient has of his own good; the good as the possibility of exercising his freedom; the ethical good. And, if the first three dimensions of the good are already considered by the principle of beneficence and by the principle of respect for autonomy, it is the ontological dimension that has to be recovered, that of being a “person” who, beyond his accidental or secondary qualities, asks for respect and protection.

Therefore, the autonomy of the patient and of the physician talk about this good, for which they have to take responsibility. And it is precisely in the ethics of responsibility that the autonomy of the patient and of the physician meet the good they are born from and for which they live. On the other hand, responsibility cannot be separated from autonomy: in order to identify the risks, harm, advantages, that a human act — any human act performed in a voluntary and free way — can produce on nature, things, men, society. This responsibility is called on in the area of gynecological oncology in at least three steps: in prevention, in the choice of therapy and in assistance.

Prevention

It is a fact that in the aetiopathogenesis of gynecological tumors, individual behavior, generically defined as “risky”, plays an important part, since it can be responsible for harming the patient’s health, and in this case, her life too.

It is enough to think about the association between cancer of the cervix and HPV, contracted most frequently by women who began their sexual activity at a young age (first sexual relationships between 15 and 17 years old) in conditions of promiscuity; or of the association between the consumption of tobacco (presence of NNK in the cervical mucus) and cancer of the cervix with reported non-progression of the histological modifications after suspension.

There is still the fear of a possible association — although the data available do not always agree — between ovarian stimulation for anovulation or in order to recover oocytes in artificial fertilization
protocols and epithelial ovarian cancer\textsuperscript{11,12,13}, whose risk is already increased in the presence of sterility\textsuperscript{14}, and breast cancer\textsuperscript{15,16}; between HRT (Hormone Replacement Therapy) epithelial ovarian cancer\textsuperscript{17}, breast cancer and cancer of the endometrium\textsuperscript{18}; between the use of oral contraceptives and breast cancer\textsuperscript{19}, especially if taken from a very early age\textsuperscript{20}; between early miscarriage or abortion and breast cancer.\textsuperscript{21,22,23}

And although it is true that a particular behavior is not always present in the etiology of a cancerous pathology, having identified this association in a high percentage of cases has to make one feel the moral obligation to modify that behavior.

In fact, health should be understood as a sort of balance that accompanies every day of one’s life and that is to be sought after continuously. Health is a job, a lifestyle. In this way, health is defined also in relation to non-medical factors, which individual and collective choices and behavior can also influence. It is in the light of this interpretation of the concept of health that promotion and prevention become fundamental: promoting and protecting health is, even more than a right, a moral obligation.

However, what form of prevention should be carried out? Two different strategies are proposed: the reduction of the risk in risky behavior and health education.

Those who propose a strategy of reducing the risk in risky behavior start from the presupposition that there are people who, despite the fact that they know about and perceive the risk, in this case the oncogenous risk, of certain behavior, consider this risk to be acceptable or, in any case, to be taken. Preventive intervention should be limited to advice which can make it possible for people to persist in that behavior but with the least possible risk. It is obvious that this way one encourages the increasing lack of responsibility of the person who practices this kind of behavior, since she can continue to impose her choices. This is because there will always be someone who is willing to suggest suitable means and short cuts, thereby leading to the increasing lack of responsibility on the part of those who should be performing prevention, and who have no interest in intervening in order to remove the cause of this incongruous risk taking.

Having the “remedy” as the aim of health education but not education itself is not enough. Real health education has to aim higher and accompany the individual in taking responsibility and acquiring full consciousness of what can improve his health and in making it possible for him to make choices in favor of his life and freedom. Health education is basically moral education. It asks for reasons for one certain type of behavior rather than another one. It aims to teach people to separate needs from desires and to help identify the jobs to be done to contribute to the protection of one’s own health, and that of others.
As is known, prevention in gynecological oncology involves, together with health education and early diagnosis, predictive genetic tests and available options such as lifestyle changes, close follow-up, chemoprevention, and even prophylactic surgery.

The use of predictive genetic tests presents the physician and the patient with choices of great responsibility (i.e., informing the patient, safeguarding confidentiality, the need to inform the patient’s relatives when they are equally at risk, the opportunity to perform tests during prenatal life). There is also a difficult evaluation of the relationship between risks and benefits, as for example in the experimental administration of tamoxifen to healthy women.

The Therapeutic Choice

The therapeutic choice is also a moment of great and shared responsibility: a choice that is usually based on the so-called therapeutic proportionality. In fact, one opts for the intervention that is considered necessary in order to save the patient’s life and to improve her health.

This proportionality is sometimes difficult to evaluate. In addition to the type of therapy, we consider the degree of difficulty and risks involved, the economic and human costs of the treatment, the concrete possibilities of carrying it out, the expected benefits and the patient’s desire for quality of life. In fact, it has been seen that only the patient, or if this is not possible, the relatives and physicians, are able to evaluate the quality of her life. The difficulty is born of distorted and utilitarian interpretations about the concept of quality of life.

In order to evaluate the proportionality of the therapies, an appropriate, constant and truthful interaction of the patient with the physician is necessary. In fact, without being able to count on the professionalism of the doctor, the patient might not have the appropriate technical or scientific knowledge to understand her situation. Without the patient’s input, and not sharing her experience, the physician might have only a general technical opinion, which may not necessarily be relevant to the patient’s condition and therefore probably not “proportional” in the full sense. Effective therapeutic choices that correspond with the personal dignity of the sick person can only derive from a real therapeutic alliance between the patient and the physician. Asking for a personal opinion in the application of the principle of proportionality means assuming that the patient and the physician are both able to understand the whole truth of the person in the concrete situation. This will be possible only if they both try and recognize the fundamental values of life and human dignity, starting from an authentic way of judging in order to achieve a humanely proportional therapeutic decision.

August, 2003
From what has been said, it appears that each time the physician wants to start therapy, he has to ask the patient for explicit and informed consent. The patient will be able to decide freely and lawfully about those interventions that have a risky and uncertain or serious outcome. However, if she refuses necessary and valid interventions, she is not fulfilling her duty to protect her life. If this happens, the patient’s refusal cannot automatically represent for the physician a lawful and sufficient criterion for suspending the therapy, since he, too, is responsible for the patient’s life and not just for her options.

A shared choice, however, means that both the physician and the patient should have the same information. This is a particularly difficult situation if the patient is not fully cognizant of the seriousness of her condition. What and how much of the truth should be communicated in such cases? When and how should this be done?

This question has been fully discussed in the literature of specialists, which indicates, on one hand, the increasing need to inform (a neoplastic pathology is no longer necessarily a fatal disease; control of the disease often depends on the timeliness of the medical-surgical intervention; knowing the diagnosis is necessary in order to start secondary prevention interventions; the need is to start the patient on a clinical trial).

On the other hand, there is difficulty in finding a balance between keeping quiet and communicating in a cold and impersonal way. In general, one must recognize the priority of the patient’s right to be informed about her state of health, even if this right to know has to be modulated by the respect due to the person, that is, one has to be careful that the information does not further jeopardize the patient’s health. Thus, the need to choose suitable words with respect to the circumstances, place, and timing, bearing in mind that informing does not mean the end of the physician-patient relationship: it is only the first step of a long, tiring and painful path.

Pregnancy and Neoplasia: Is there a Mother-Fetus “Conflict”?

The choice of therapy is more complex when one has to intervene in the presence of a pregnancy. Should the woman be treated as if she were not pregnant, or is it necessary to bear in mind that there are two patients, the mother and the fetus? Should one carry out therapy or not, knowing that it may harm the health or endanger the very life of the fetus?

Moreover, there is another question for those who also take into consideration the possibility of abortion: can abortion be considered a form of “therapy” for a mother with cancer?

Let us first study this last question. Abortion can never be justified, even out of a desire to avoid harm to the health and life of the fetus (no
harm can be more serious than an inflicted death) or out of fear that continuation of pregnancy may accelerate the evolution of the maternal pathology. Regarding this question, one can refer to studies carried out on the association of pregnancy and breast cancer, which indicate that pregnancy does not directly contribute to the development or to the acceleration of breast cancer, although one must point out that the physiological conditions of the breast during can delay diagnosis.\textsuperscript{32, 33, 34} It has also been shown that sometimes when an abortion is suggested to reduce gynecological pathologies, melanoma for example,\textsuperscript{35} the fetus is actually the one in greater danger.

So how should the presence of cancer in pregnancy be managed? Three different situations can occur: 1) The therapeutic intervention can be postponed until the end of pregnancy; 2) The therapeutic intervention has to be carried out once the diagnosis has been made; 3) The mother refuses any therapeutic intervention.

In the first situation, this would be a question of waiting for delivery, which is sometimes anticipated as soon as the pulmonary maturity of the fetus has been ascertained, in order to intervene medically and/or surgically. This is the case, for example, of cervical cancer. It has been shown that a mean delay of 16 weeks between the diagnosis of stage IB cancer and the beginning of therapy, coinciding with delivery, did not negatively influence the course of the disease.\textsuperscript{36, 37}

In the second situation, which is the most frequent one, a delay in therapeutic intervention could accelerate the evolution of the disease also with the risk of the woman’s death during pregnancy. That would mean the loss of both mother and fetus. Therefore, on one hand there is the need to begin the therapy as soon as possible, and on the other hand, the responsibility for the health and life of not only the mother, but of the fetus as well.

In these situations, the therapeutic choice will have to be adapted to the mother’s clinical situation, although the physician will have to bear in mind that there are forms of treatment that can harm the fetus, depending on the phase of development reached. In fact, it is known that while there are no contraindications for the use of anesthetics in pregnancy, radiotherapy, even in extra-abdominal areas, can have an abortive or teratogenic effect. Chemotherapy has different effects depending on the period of the pregnancy: abortive and teratogenic effects during the first trimester; induction of pre-term delivery, inter-uterine growth retardation, and the possible appearance of tumors in the fetus in the second and third trimesters.\textsuperscript{38}

On the other hand, some follow-ups demonstrate that there have been no negative effects on fetuses whose mothers have undergone surgery or who have been treated with chemotherapy in any trimester of August, 2003
pregnancy. Therefore it will be necessary to opt for the therapeutic intervention that harms the fetus as little as possible but does not deprive the mother of the necessary support.

One certainly cannot overlook that the therapy can harm the fetus or even cause a miscarriage, but these occurrences can be justified from an ethical point of view, even though they are not directly desired. This is known as a double effect action; that is, in looking for the positive aim of the action (curing the mother) and in the absence of other risk-free remedies, one can accept the negative, foreseeable and inevitable effect (disease or miscarriage) but this is not directly desired.

As previously mentioned, this double attention with respect to the mother and the fetus often occurs only if the woman has decided to proceed with the pregnancy, as though the existence of the fetus acquired dignity following the mother’s choice. Now, no one can deny that the connection between the mother and her child is very strong. No one is in a position to make the best choice for the mother. It is also true, however, that it is the physician’s duty to present the clinical reality of the case in the most objective way possible so that the decision is made in full awareness.

In this clinical reality, one should also include the personal and objective reality of the fetus, whose dignity should be recognized by everyone and, above all, by the mother who is carrying him. She will certainly bear the greatest weight of the decision, especially in the third situation, the heroic decision not to undergo any therapy.

The “Subsequent” Responsibility

Finally, there is a last responsibility that concerns those who are involved in assisting the patient. That is the management of suffering, the unknown, the risks of the disease and the confrontation with death, all of which require assistance in addition to medical, of a psychological or spiritual nature, and is often lacking.

A study carried out at oncology centers in Norway on 600 patients with tumors is indicative in this sense, since there is an increase in faith following the disease (an increase of religiousness in 24% of cases). This does not, however, correspond to a general provision of religious assistance, which is only provided in 57% of cases and on request. In fact, there seems to be a strong need to give a sense to the disease, to pain and to death, thus, the need for global assistance.

When this assistance is lacking, it is inevitable that there appears the request to end one’s existence, a request for euthanasia. And in fact, it is hypocritical to think of justifying euthanasia in the name of excessive technologicalization of medicine. There is a different reason. It is suffering and death that frighten people; it is being abandoned that makes people
vulnerable; it is the lack of charity and of solidarity by those assisting that pushes people toward an extreme choice. Actually, since euthanasia is an act totally against nature, one has the feeling that the patient's request is not dictated by her desire, which changes with time, but is rather the expression of a wish that is communicated, certainly not consciously or verbally by those assisting, who have become consumed and tired of being inert spectators to so much suffering, and who are unable to bear their own fragility and that of others.

References


192

Linacre Quarterly


August, 2003


