

## **Nil prodest quod non laedere possit idem - The intangible side-effects of medical technology**

*Dr. Tjeerd Tymstra*

*Department of Health Sciences, University of Groningen/The Netherlands*

*Every medical technology has both advantages and disadvantages. The disadvantages are often intangible. Transplanted patients, for example, feel that they have to be grateful, and they can experience this obligation as a heavy burden. In coping with screening technologies and probabilities of disease, people tend to make their decision via binary thinking (whether the chance of having something serious is 1 in 100 or 1 in 100,000, a chance is a chance) and want to avoid feelings of regret. In this way, a Faustian spiral of choice-giving technologies together with the avoidance of feelings of regret results which takes on an increasingly uncontrollable character.*

Five hundred years after PARACELSUS we are living in the age of the technological revolution. No one will deny that the developments in the field of science and technology have changed our world fundamentally. What would the world look like without all the modern technical achievements? It is, of course, impossible to answer such a question.

Imagine that organ transplantation had turned out to be a useless technology because not one single organ could function in someone else's body. The world would certainly have looked different: a large group of people would no longer be alive and many relatives would be mourning the loss of a loved one. But others would not have been confronted with the consequences of technological failure (unsuccessful transplants), or the bitter after-taste of a «missed chance» because no donor organ became available. If there had never been any organ transplantations, many parents whose child had been killed in a traffic accident would not have been able to comfort themselves during the mourning process with the thought that someone else could carry on living thanks to their child's organs. But then again, there would never have been a mother who, after having given permission for her son's organs to be removed, had felt deeply sorry. We studied this subject and I remember very well a woman whom I interviewed. Suddenly she started crying and left the room, and when she returned she told me that she could not bear the idea that they had cut up her son's body, of which he was so proud.

### **Advantages and disadvantages of medical technology**

Twenty centuries ago OVIDIUS wrote «Nil prodest quod non laedere possit idem»: every medical technology has both advantages and disadvantages. For every medical technology it can be said that «it is a pity for some that it was developed», although it is not always easy to say to whom this applies and whether the people involved will experience it or express it in this way. *Penicillin* can be regarded as a blessing for mankind but some would have been better off without it: those to whom it was administered too fast or in too large a quantity.

Let us take as an example the *in vitro fertilization* technology. The majority of sterile women who undergo *in vitro fertilization* will never have a baby: wouldn't it have been better for them if *IVF* had never been developed? No one can answer this question. The average success rate in Western *IVF*-clinics is between ten and fifteen per cent. But what would we have done if it had appeared to be much lower?

We conducted a survey among a group of women who were on the waiting list for *IVF* and found that even if the chance of success was only two per cent almost two thirds of them would still choose in favour of *IVF*. Would such a low success rate be reason to withhold the *IVF* technology from the public because we find it unacceptable that so many women undergo an invasive therapy and hormone treatment for nothing? And what about the investment in manpower and means? Isn't it unethical to spend so much money on a half-way technology whereas, in many Western societies, it appears that we are more and more incapable of providing adequate daily care (feeding, washing etc.) for handicapped people or dementia patients?

It is clear that modern medicine offers us a lot and everyone is profiting from it (at least in the Western societies). But more and more medical technologies are subject to discussion and are therefore controversial. This is especially the case with the ever increasing number of screening technologies, for example *gene carriership screening* (one sometimes gets the impression that researchers and doctors are becoming increasingly worried that many people are not worrying yet). In the Netherlands - as in many other countries - there is discussion about the acceptability of screening carriers for the *cystic fibrosis gene*. One in thirty inhabitants (three per cent) carries the *CF*-gene, which means that one in 900 couples are both gene carriers and those couples have a 25% per cent chance that their child will have cystic fibrosis. The gene has been found on the seventh chromosome, and the DNA-test only costs a few dollars. A screening programme no doubt will be cost-effective. So why not offer this gene carriership screening to all young people who are in the reproductive phase of their life? It is clear that in these cases we should be aware of the social consequences of the technology.

But what exactly are they? A technology should do more good than harm, but the problem is that in this case the harm is *intangible*.

### **Quality of life**

Some medical technologies are controversial because of their effects with regard to the outcome of the technology in terms of «quality of life». The term «quality of life» has become a key concept in modern medicine. Policy-makers are asking for hard facts about medical outcomes, and a large number of instruments have been developed for measuring health status and subjective well-being. They are used, amongst others, in the field of organ transplantation, and these studies usually give a positive picture of the subjective well-being of the patients concerned.

This was also apparent in our evaluation of the liver transplantation programme at the university hospital where I work: the questionnaires demonstrated that, on average, physical recovery was good, and most respondents considered themselves healthy. On the scales of «well-being» that were presented to the transplanted patients, the average scores were high, sometimes even higher than those of the average «healthy» population.

This quantitative data, however, is not very informative if we are interested in the patient's individual experiences (his hopes, fears, disappointments, etc.). Therefore, a qualitative approach is desirable. In the liver transplantation study we made use of in-depth interviews and found that, in comparison to the information derived from the questionnaires, the image was less homogeneous and also less positive. Many respondents had experienced varying degrees of psycho-social problems, and in some cases we were confronted with serious problems (depressive complaints, suicide attempts). The problems not only appeared to arise shortly after the operation, but also many years later. The extreme, favourable picture regarding the quality of life emerging from the answers on the questionnaire had to be put into perspective.

How can the discrepancy between the quantitative and qualitative data be explained? There are, of course explanations of a general psychological nature (such as «adaptation» and «cognitive dissonance»). But there are also more specific clarifications. Many transplanted patients expressed the feeling that they have to be grateful to the donor and to all who did their utmost to maintain the patient's welfare (the doctors, nurses, their family). This gives them the obligation to be positive and optimistic, and they can experience it as a heavy burden that they have to be happy and are not allowed to complain.

The evaluation of transplant technology is particularly focused on the functioning

of patients following a transplant, and we always see pictures of happy patients and families who do so well after the operation. But there are, as was stated before, more people and aspects involved which require attention.

In our study, we also paid attention to the drawbacks of this technology. We interviewed the relatives of patients who had been turned down for the transplant – and died. A large proportion of the respondents were left with negative feelings concerning their involvement in the transplant programme. Bitterness and resentment were not uncommon. Two thirds of this group of relatives agreed with the statement: «The loss of a loved one is more difficult to cope with if a liver transplant had appeared possible».

We also interviewed the relatives of patients who had died during or after the transplant. We asked this group of respondents how they felt about the whole affair, looking back. «I'm grateful that my wife could have the chance; they did everything they could for her», was the answer of a man whose wife died some months after the operation. But others were left with negative feelings, and for them, the involvement in the transplant programme meant an extra burden. Five of the 14 relatives agreed with the statement: «If the possibility of a liver transplant had never existed, it would have saved us a great deal of problems and worry» (three disagreed, six were neutral).

### **The technological fix**

Modern societies are very technology-oriented. But it should be realised that every technological solution to a problem disturbs a certain balance and gives rise to other problems in adjacent fields for which, in our rational-technological society, further technological solutions must be found (the *technological fix*).

Transplantation technology is a clear example of such a development: multi-organ transplants, marketing of organs, increasing waiting lists, artificial organs are facing us with new moral dilemmas. These dilemmas are also present in the case of the reproductive technology, which is my second example. Many diagnostic procedures can inform us about the condition of the fetus. Everyone is familiar with technologies such as *amniocentesis* and *chorionic villi sampling*. However, these technologies are rather invasive and expensive, which means that they are not suitable for screening procedure. But the discovery of the micro-cosmos goes on and on, and nowadays new tests on blood samples from pregnant women are supplying us with more and more information about the fetus. Together with maternal age these biochemical markers can be used to assess the risk of *DOWN'S syndrome*. These blood tests can be used for large scale screening programmes. If all the two hundred thousand pregnant women in the

Netherlands were screened and if the group with the highest risk received further examinations such as amniocentesis, then 60 per cent of the children with DOWN's syndrome would be detected (which is twice as high as when using only the age-selection criterium, which in the Netherlands is 36 years).

The Dutch government has reservations about this mass screening. At some Dutch teaching hospitals, experiments are carried out with these new serum markers. The blood test leads to situations in which a normal twenty-eight-year-old pregnant woman is told that: «The results of the serum test show that your risk of having a child with DOWN's syndrome is not 1: 1,100, but 1 in 185 (which is higher than the risk of a thirty-six-year-old pregnant woman who has the right to make use of amniocentesis).

We performed a study examining how women, who had been told on the basis of the serum test that they ran an increased risk of giving birth to a child with DOWN's syndrome, coped with this information. We interviewed twenty younger pregnant women and we found that the participants were not very well informed about the meaning of the serum test. Those who received the news that the test had indicated an increased risk of giving birth to a child with DOWN's syndrome found it very stressful. The women did not think in terms of «now I run a greater risk», but were more or less convinced that «there is something wrong with my baby». Consequently, the majority of women were determined to undergo amniocentesis to be certain. They say «I can't get through these nine months with such a feeling of uncertainty; I've got to know for sure whether there is anything wrong.»

### **Psychosocial consequences**

With these tests we are interfering with the normality of pregnancy, because every woman is faced with a new choice, a choice that makes her responsible for the outcome, whether she uses the test or not. It is also apparent that technologies such as the maternal serum-screening have an impact on society as a whole. Offering these screening tests may lead to what BARBARA KATZ ROTHMAN called *The Tentative Pregnancy*. Before long, all pregnancies will have a tentative character: women will not be or feel pregnant until a series of tests has been carried out in the first few months of pregnancy and the results of these tests are all favourable. Moreover it will mean that in the future no child will be born unconditionally any more, that every mother will have put conditions on her child («I did want you but first had checked whether you were o.K.»).

These macro-sociological implications of technological developments cannot be verified operationally - much less can they be measured. But they should be

taken seriously. When are the negative side-effects of a screening reason to withhold the test from people? How much anxiety and how many disturbed pregnancies weigh up against the detection of one defective fetus? In our Western society, many consider it an unacceptable form of paternalism if it is decided to withhold these kinds of technologies from people: everybody should decide for her- or himself about the usefulness of a certain technology (the autonomy-principle). But how far should we go?

Many new medical technologies involve chances and therefore could be called *choice-giving technologies*. How do people deal with this sort of data and which chances and risks do they find acceptable? In order to gain more insight into these problems, we conducted a study in which we asked a group of young mothers the following question: «Would you take your newborn baby to a screening clinic and leave it there for 24 hours to undergo tests for the early detection (and adequate treatment) of a serious disease which occurs in 1 in 90.000 cases?». Over one third (38%) of the respondents said they would participate. We were surprised by this result. Even after having presented the drawbacks of such a screening test (separation of mother and child, interference with breast feeding, car accidents etc.) many of the respondents remained in favour of screening.

We presented the following question to a group of blood donors: «Imagine that you underwent a medical procedure with a risk of becoming contaminated with AIDS of 1 in 5 million, would you worry about it?». Half of the respondents indicated that it would worry them. We then asked: «Would you be prepared to make a financial contribution to exclude this risk?»

Almost half said that they would be prepared to pay, and one third of them would pay a week's wages or more.

Why does such a minute possibility induce so many people to behave in this way? Two factors play an important role. In the first place psychological research has shown that people in such situations tend to make their decision via binary thinking. Whether the chance of having something serious is 1 in 100 or 1 in 100,000, a chance is a chance people argue, and even if the chance of a positive result is small, they will say «suppose that one person is me». Another explanation is that in the decision-making process people are influenced, among other things, by the anticipation of the feelings that might arise if it should appear that they made the wrong decision; people want to avoid feelings of regret. This «anticipated decision regret» can explain that people often find it very difficult to refuse the medical technologies offered to them. This can be illustrated by a citation from an interview with the wife of a liver patient who died six months after the

operation: «You often find yourself wondering whether it was all worth it. But if we'd decided not to do it, my husband wouldn't have been here now either and you'd always have been left with the regret that you hadn't tried everything». And many women on the *IVF*-waiting list stated: «Now that the *IVF* method exists I feel that I should make use of it: then at least I will have tried everything possible».

We are living in the age of the technological revolution. Science will continue developing choice-giving technologies – a *Faustian* dilemma? People show a strong tendency towards averting every chance of an approaching calamity and will go to great lengths to avoid feelings of regret. «At least we tried everything» is what people tend to say. Moreover, it is considered an unacceptable form of paternalism if it is decided to withhold these choice-giving technologies from the public. In this way, a spiral of science, technology and efficiency arises which takes on an uncontrollable character. Five hundred years after *PARACELSUS* we have to ask ourselves: are we selling our souls to technology?

*Further reading*

HEYINK JW, TYMSTRA T. Liver transplantations: a success in most cases. But what about the less fortunate patients? *International Journal of Risk & Safety in Medicine* 1993; 4: 103 – 115

ROELOFSEN FCC, KAMERBEEK LI, TYMSTRA T. Chances and choices. Psycho-social consequences of maternal serum screening. A report from the Netherlands. *Journal of Reproductive and Infant Psychology* 1993; 11: 41 – 47

TYMSTRA T. The imperative character of medical technology and the meaning of „anticipated decision regret“. *International Journal of Technology Assessment in Health Care* 1989; 5: 207 – 213

DE ZOETEN MJ, TYMSTRA T et al. Waiting for *IVF*: Motivations and expectations of women who entered an *IVF* programme. *Human Reproduction* 1987; 7: 623 – 626

KATZ ROTHMAN B. *The tentative pregnancy*. Viking, New York 1986 (Deutsch: Schwangerschaft auf Abruf. Metropolis, Marburg 1989)