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For Better Relations Between Science Professionals and the Public: What 'Informed Consent' Suggests Us

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Abstract: The paper suggests that the professional community of science and technology accepts the idea that the public, not the professional community, has the right to decide on its own judgement some sorts of matters concerning science and technology, even though the public has no technical knowledge of the subject. The paper also proposes that professionals assume the responsibility of giving full explanation of what is necessary for the public to make their judgement. Then arises a question: can the lay public really understand scientific and technological matters? The paper gives a positive answer to that question by recourse to the underlying philosophy of informed consent in medical practice. The fact that patients with no technical knowledge have successfully carried out informed consent presents the reason to answer the question affirmatively: what laymen need to understand is so limited that they do not need to understand at the same level of profoundness that professionals do. A body of knowledge which is at a layman's level plays an essential role in making wise judgements. It is also pointed out that opportunities to seek for a 'second opinion' is to be secured and that the idea I propose does not imply the distrust of professionals.

Key words: history of science, informed consent, public understanding of science, scientific debate

1. INTRODUCTION

Mutual trust between professionals in science and technology and the public or non-professionals seems to have been shaken recently. Professionals complain, for example, that the lay public does not assure the right amount of financial support for their research nor pay proper respect for their achievements, while the public is anxious about what the professional would bring about in the world. In what follows, I will suggest a principle, which I believe if it would be adopted by professionals, would improve the deteriorating relationship between laymen and professionals, and then argue, with the help of our experience of adopting the system of informed consent in medical practice, that the principle is indeed effectual. It should be noted here that it is not my claim that the procedure itself of informed consent, if adopted in the cases concerning science and technology, would be effective.

2. THE PRINCIPLE TO BE ADOPTED

What most obstructs our building up good understanding between professionals and the lay public is the remark often uttered by professionals to the effect * : "leave everything concerning science and technology to us professionals, as we surely would handle it in your favor." That kind of remark has often disrupted cooperative relations between professionals and the public, even if it was rooted in good intentions of the former. Hence, professionals should now accept publicly the principle that it is not the professionals in science and technology, but the public who has the authority to decide such matters as the following: the kind of research which is allowed to be carried out; the extent to which financial support for further research is given from national budget; whether or not possible detrimental effects resulting from a new outcome of a research would outweigh the benefits.

Indeed, it is members of the professional community who really carry out research. However, they can only do it with the approval and the support of the public, and hence they are allowed to conduct their research within the field permitted

*A professional in a field of science or technology is, in most cases, non-professional or a layman in other fields of science or technology.

and within the limit of the budget provided. In this sense, sovereignty of science and technology resides with the public, not with professionals who constitute only a small portion of the members of society. †

The idea that the lay public does have license to make decisions on scientific or technological matters which may affect their lives is comparable to the idea of 'the right of self-determination' implied in 'informed consent' in medical practice. The right is opposed against the paternalism of doctors or the professionals in medical practice.

With the authority vested to make decisions by themselves about scientific or technological matters which they are seriously concerned about, the lay public can protect themselves from 'good will' which they have been forced to accept by professionals —— compelling the public, for example, to adopt a new technology, saying that it will no doubt make your life comfortable (as, in the case of medical practice, prescribing a treatment only to prolong a patient's life with no regard to his quality of life). People can, with the authority, prevent professionals from having their own way —— conducting themselves only for the best interest of their professional community (as carrying out unnecessary medical check-ups on a patient in the expectation of a better sum of reward).

People in Japan are now highly educated in science and technology and have great concern about scientific and technological matters. They therefore will not be satisfied with the assertion by professionals that laymen have no right to interfere in scientific nor technological matters simply because they are not professionals in the field. Besides, people now perceive that professionals in science and technology are not necessarily those who assure them a glorious future, in spite of what professionals pledge. They have already discovered that 'paternal affections,' so to speak, of science and technology professionals are not always beneficial for them.

3. OBLIGATION TO GIVE A FULL EXPLANATION

It is needless to say that one should not make decisions blindly but they should be made on the basis of a full understanding of the matter. Accordingly, in order for him to make an appropriate decision, a patient is given the right to ask his medical doctor for an explanation which is understandable to him and helpful in his decision-making. (A doctor has, on the contrary, an obligation to give a full and understandable explanation to his patient.)

This apparently imposes a heavy burden on professionals. When a patient who is not a medical professional claims that he cannot understand the explanation given by his doctor, the patient is not to blame for this but the doctor is. The burden of explanation is to be laid on professionals to offset crucial difference in 'power', since the difference in 'power' arises from the fact that a patient or a non-professional has much less knowledge about the matter than a doctor or a professional, and it is the difference in the amount of professional knowledge that has kept paternalism of medical practitioners tenable.

The same can be said in the case of science and technology. In order to promote a frank and candid exchange of views between professionals in science and technology and the public, it is extremely helpful to impose a burden of explanation on the former. The reason is that a professional is apt to show an attitude toward a layman that implies: 'you do not have enough knowledge to say anything in this technical matter', while a layman is likely to quail at an 'enigmatic' explanation filled with technical jargon. Laying the burden on professionals will help maintain the balance of 'power' between the two parties.

4. EVEN A LAYMAN CAN UNDERSTAND

Here arises a question: Can a layman really understand technical matters in scientific or technological problems? If he cannot, informed consent is not tenable in the case of science and technology.

Hints for answering the question positively are contained, I would argue, in the fact that informed consent in medical practice is thought to be feasible and has been carried out successfully in some advanced countries. This fact shows that even a patient who is not a medical professional can fully understand what is needed for him to make his independent decision about his medical treatment. Why can he fully understand it? I will show that there are two reasons, which will provide us clues to reply "yes" to that question raised at the beginning of this section.

4.1 The extent and profoundness is limited

In informed consent in medical practice, what a patient should decide is largely limited and all he has to understand is what relates directly to his decision-making. Suppose, for example, that a person goes to a hospital and is diagnosed as having a cancer of the tongue. He will get an explanation from his doctor of the disease with some X rays and various clinical data before him. He will also have a full account of some reasonable choices of treatment, with information of therapeutic ratio, the degree of potential side effects and a prognosis of each treatment suggested. All the patient should understand in this circumstance is what is requisite for his choice of treatment: what is the meaning of the number of therapeutic ratio; how will the side effects pointed out (decrease of the number of white blood corpuscles, for example) unfavorably affect his life, and so on. He need not understand

† I discussed the point in more detail in [1].

how the X rays before him can be read nor to realize why the cancer cells are destroyed by X-rays applied to them.

The same can be said in the case of science and technology as in the case of medical practice. Suppose that a dispute has arisen between science professionals employed by a company which produces instant noodles and its consumers [‡]. In the dispute they debate whether a cup made of foamed styrene resin is suitable for enclosing instant noodles in it. The point at issue in the dispute will be, first of all, whether styrene dimer or styrene trimer dissolves out from the cup when boiling water is poured into the cup to cook the instant noodles contained in it, and then even if styrene dimer or styrene trimer is indeed found to dissolve out, whether they cause any harm to human with the amount detected. Although these issues are critical in the dispute, consumers who are deeply anxious about the harmfulness of using a cup made of foamed styrene resin as a cup for instant noodles are not required to know, for example, how the chemical reactions occur which are used in detecting styrene dimer and styrene trimer.

As the example shows, what non-professionals should know when they make a judgement about a specific matter related to science and technology need not be so abundant nor extensive. It is hardly necessary for them to understand the same thing with the same profoundness as professionals.

Consider a knowledge spectrum with professional and non-professional knowledge at the respective ends. Then, we can say that it is at a certain point in the spectrum when a dispute arises, that the dispute will be resolved by the process of discussion between professionals and the public or non-professionals. Laymen need not know the whole spectrum of knowledge to form their judgement.

4.2 Non-professional knowledge is essential

When a patient gives his consent to the treatment suggested by his doctor, he would often take into account essential aspects of the matter other than that which can be dealt with by medical science, as well as the medical informations given. As to this kind of aspect, a doctor can no longer be qualified as 'professional'.

Consider, for example, the case in which a patient who is diagnosed as having a cancer of the tongue makes a choice between surgical treatment and radiation treatment. In making the choice, he would have to take into account the QOL or quality of life after being treated; surgical treatment would cause in all probability impediment in his speech, while radiation treatments would not, though it cannot cure the cancer completely [§]. It is quite understandable from the point of view of his QOL that he would choose, in these circumstances, radiation treatments for the reason that he might prefer a joyful, though short, life to eradicating cancer cells. Appraisal of this nature is beyond the reach of medical science itself, however.

The same can be said in a dispute concerning scientific or technological matters, too. Consider again the dispute supposed before over the possible harmfulness of a cup made of foamed styrene resin. When consumers claim that the cup is harmful to humans, they believe the company producing the instant noodles should provide another choice of cup rather than clarifying scientifically whether it is really harmful or not. The alternative choice they think of amounts to establishing the principle that producers should not enclose instant noodles in a cup made of foamed styrene resin irrespective of its being proved harmful to humans. Consumers do not seek a final and definite solution to the scientific problem of possible harmfulness, but rather demand to pay the highest regard to the principle that we should wisely refrain from using material that ***may possibly*** be harmful. The principle is of the kind which cannot be derived from purely scientific reasoning. It is, so to speak, out of the context of genuine science, as the QOL is out of the context of genuine medical science.

For those who deal with everything within the framework of science and technology, the principle referred to will be hardly acceptable, for admitting the principle means to treat the material of which harmfulness is not yet proved as if it has been conclusively proven. It is similar to the case in which a doctor is forced, for the sake of QOL his patient claims, to give up the treatment he considers the best from the point of view of medical science.

As the argument has shown, a body of knowledge or philosophy which does not belong to any specific field of science and technology plays an important role in settling a scientific dispute as in the process of informed consent. That the general public lacks academic or technical knowledge of science and technology, therefore, does not necessarily cause them unsurmountable difficulty, but rather presents them as having precious intelligence. It can be said, on that ground, that the 'non-professional' end of the knowledge spectrum stands not for the lack of professional knowledge of science and technology but rather for the possession of 'knowledge of another kind': knowledge of society or economy, or philosophy about the desirable way of life, for example.

5. THE RIGHT TO GET SECOND OPINION

It is certainly conceivable that there will sometimes be cases in which laymen cannot understand the explanation professionals give them, or cannot be fully convinced of it, in spite of their earnest and wholehearted effort to give easy to understand, clear, and unbiased explanations. In such cases,

[‡]For actual debate about the matter, see for example [2].

[§]This is, needless to say, an imaginary example.

the laymen may ask another group of professionals for their opinion or advice. The opportunity to seek another opinion must be securely afforded to them. Another opinion which will be sought in this case is the equivalent of 'second opinion' assured in the process of informed consent.

Another group of scientists may be able to restate the explanation given by the first group of scientists and found difficult to understand by laymen. Furthermore, another group of scientists may be able to help the public express their naive and intuitive doubts or vague and indescribable anxieties in such a way that the academic circle can understand. The group will accomplish it by formulating them in terms of technical jargons.

Non-professionals may, in some cases, not wholeheartedly be convinced of the explanation professionals gave them: they may have some doubts about the validity of assumption professionals made, or they may feel difficulty in agreeing professionals' assessment of data. Even professionals, in both science and technology as well as in medical practice, are not in total agreement on many issues. In these circumstances people need to be insured of the opportunity to have access to the opinions of groups of scientists in whom they can place their trust. In addition, 'second opinion' helps the public consider scientific matters on their own without being blinded by 'authorities'.

The importance of the right of self-determination manifests itself here again. The right would protect the people who try to get a second opinion from possible obstructions. Furthermore, if non-professionals do not hold the right to adopt, on their own judgement, the second opinion they acquired as a reasonable choice, the right of seeking second opinion comes to be worthless. The right of self-determination, therefore, must be established first in order to make it meaningful to ask for a second opinion.

6. IT WORKS JOINTLY WITH 'TRUST'

Some in the medical profession are of the opinion that informed consent would damage the relationship between a patient and a doctor, since the idea of informed consent is based on patients' distrust of doctors. ¶

However, I think that the system of informed consent works in conjunction with trust: trust in the knowledge that medical professions do have. Think again of the cancer patient I mentioned before. He has no doubt about X rays which help discover the region of a cancer, various data obtained by medical examinations, medical theory which predicts the effect of a treatment, and so on. Again, consumers who regard the unharmfulness of the cup as questionable have no doubt about, for example, the theory of chemical reactions which is indeed applied in detecting styrene dimer and styrene trimer.

Thus a great deal of professional knowledge which is not concerned with the point at issue is not at all disputed in informed consent nor in any argument concerning science and technology. That is to say, non-professionals believe in the knowledge professionals have, and rely on their judgement. It is because people believe in the validity of nearly the whole body of knowledge that professionals claim to have, that a small specific part of knowledge can be contested.

This does not mean, however, that a line is firmly settled in the body of knowledge, beyond which non-professionals are unable or not allowed to enter to discuss its validity. When we think that the line is immovable and fixed at the same place regardless of the question at issue, we are easily led to the view that the public with no professional knowledge can say nothing about technical matters in science and technology.

A dialogue between the lay public and professionals is, in this sense, a process of rebuilding trust between them. The public claims only that professionals should acknowledge the validity of appraisal which non-professionals made of a specific point of issue, leaving most other parts uncontested. Thus, neither a dispute between the lay public and professionals nor a process of informed consent between a patient and his doctor dismiss people's trust of professionals. Or rather, either can only occur with confidence in professionals.

¶See, for example, [3].

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