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E-Health and the Informed Patient
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Dear friends,

This title is interesting and important from several different perspectives;

Patients throughout Europe meet new challenges in new therapies as well as new knowledge regarding their diagnosis.

The new knowledge is not always easy to understand or to apply in their life.

The currently existing health care system is not designed to meet this new situation.

I would like to focus on the need to provide information to the patient and what it means in practice, especially in an organization such as Agrenska that I will speak about.

All of us have been or are going to be a patient at one time; either because you will have to look for help from the health care system e.g. hospital or you want to improve your own health because you want a better quality of life.

My point is that all of us have an interest in our own health, and we are always passively or actively looking for something that could improve our health.

During the last decades the scientific opportunities and medical breakthroughs have made enormous impact on the quality and length of life. And more is to come even faster than before. With the incredible biomedical developments today it is possible to get a cure or a treatment somewhere on earth, for nearly any health condition. This doesn't mean that you can cure every illness and get healthy, but it means that you can improve your health conditions enormously better than before.

But there are of course some obstacles that have to be overcome. And there is a lot of new knowledge to be developed in order to really cure illnesses.

Let me mention just a few;

The need to get drugs faster to the patient

The need to provide safer and more targeted products

The need to develop new way of cooperation between the patient and many different partners, such as pharmaceutical companies, government, academic, scientific or health professional organizations.

The possibilities in this are great but impossible to achieve without providing greater information to the patient as the patient's role will grow in the future. This is not limited to greater individual responsibility and compliance. The patients in the future have to be much closer involved in stimulating research and facilitating clinical trials through better and smarter information technology directed in predicting risks and benefits.

Finally there is a need to exchange information to patients around the world in a trustworthy secure way.

This is all good, but this is not in general yet the situation of today. We have to develop many more situations and places where this interaction between the patient and the different partners can take place, as I mentioned earlier. The interaction doesn't occur only because we create a meeting or, we send out a survey, or we ask the professionals.

Information to the patient will need cooperation in the circumstances that meet certain standards.

One example of such a meeting place where patients get informed is an organization such as Agrenska in Sweden. In fact Agrenska is dedicated to the provision of information not only to patients but to the entire families and it serves as an information exchange for the specific groups of patients and the specific diagnoses. Agrenska is focusing especially on rare diseases in children and their families. Since the beginning of 1989 more than 3 000 families have participated in our different diagnosis related family programs. As these diseases are rare the need for information is particularly intense. And as these conditions affect the children, their impact on families and society is that much more profound.

It is within the Family program at Agrenska this interaction take place. Children who are already identified by the medical system come to Agrenska with their parents and siblings because they all need information. Here, the meeting takes place between many different partners, such as researchers from pharmaceutical companies, government, academic, scientific or health professionals, and the patient.

Together with Microsoft Agrenska have developed a virtual platform on internet (www.agrenska.se/familyprogram) for the use of the children and their families. They can use it either to exchange experience and thoughts after their visit at Agrenska in the chat forum where they also can exchange information together with the experts that they met during the visit. The children can use their "picture diary" to exchange information with their friends or/and the professionals they meet regarding their disease.

This form of interaction is very important because the information with respect to the conditions seen at Agrenska, have to come directly from the different actors, and it is equally valuable that the information go back from the patient to e.g. the researchers, or to the health care system.

The benefits of this program are undoubtedly recognized not only in Sweden but also internationally. This can be seen by the interest from different institutions and companies worldwide. Some of them who have seen the program as important are; - NIH, Eurordis, University and Hospitals in Estonia, Orphan Europe, Universities in Sweden, Microsoft, different patients org. in Japan, the Middle East, and South Africa.

This means two things;

The need is the same regardless where on earth you live

This meeting place can be used in all kinds of cultural and government environment.

Without the involvement of Microsoft as information technology provider there would have been major obstacle in the process.

A report done at the School of Economics and Commercial Las in Göteborg has shown in 1997 that the health care costs with respect of the children who have not gone through a tailored information family program, was notably higher than those of treated children. The cost of health care for non-treated children amounted to SEK 35 200 per annum, in comparison with those of treated children in the amount of SEK 13 300 per annum, or three times more.

The difference could possibly be explained by the fact that the informed family new;
When they should seek medical care for their child
Where to go, and whom to ask for care
How they should proceed
When they didn't have to go to the hospital, because they could manage them selves.

I would say that this is the way an informed patient/person acts and behaves, and that is why they cost the society less than the uninformed patients.

So the question is;

Who wants an informed patient?

Today we live in an individualistic society, and all the signals are saying that each one of us should make the decision about everything from our pensions to what kind of profile we want on our children's school.

So the answer may be that we already have left the uninformed city into the ones where you have to be informed in order to coop.

There are still some high ranking doctors in Europe who think that is totally wrong that the pharmaceutical industry has their own contact direct to patient's organisations.

How can a patient be informed?

State

Patient's org.

The different companies who deliver the services, e.g. a pharmaceutical industry

Other bodies

Based on science and good standards

Must every patient be a well-informed patient?

No, and that is important from a democratic point of view.

Knowledge should never be that kind of important power.

What differentiates an informed patient from an uninformed patient?

Everything, a feeling of receiving more appropriate treatment, a better sense of well-being and ultimately better quality of life.

Who will take the responsibility to change the way healthcare services are organized today, in order to meet the needs of the informed patients?

The only ones that have that kind of authorities are the politicians. And if the don't do it, I think their voters will force them to do it, either directly through elections, or by the numbers of services who will be run by private persons or independent companies.