

# The patient as a partner in promoting healthcare policies and research

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## The Patient is a Problem or the Patient has a Problem?

- Normally the **patient** is considered by the Health Care System, the Government or the society in general, as a **big problem**.
- But we should say more correctly, that the **patient HAS a problem**, or some problems.
- The patient must go often to the doctors, to the hospitals, to the driving commissions, to the pharmacies, and loses a **lot of time** for all these kind of things, time that other people can use for many better and interesting activities.

## How much do you cost?

- But we are used to consider the patient as a **cost** for our societies, which surely is true.
- The **economical crisis** in Europe, but also the equally critical disparity in the average economic situation of families in developing countries, and, not least, in many of the leading developed countries, induces societies to look with a terrified blank expression to the needs of patients affected by chronic pathologies.

## I'm starting having some fears...

- The patients, and the Associations of patients, are really scared of all this environmental pressure on costs.
- **What will they cut next?** It's a really normal feeling at this time.
- And the clinicians in the Hospitals, the Sanitary Authorities in the local administrations, the various Ministries of Health worldwide? All scared and apparently unable to find the way out.

## Has someone a *Final Solution* in mind?

- Do we really have to cut the therapies to cut the costs?
- Do we really have to cut the number of clinicians and nurses to cut the costs?
- **Do we really have to cut the patients to cut the costs?**
- Do we really have to accept that the developing countries face their problems of health by themselves without an aid?

- Does all this will really mean an intelligent way to spare and create a better future?

## YOU, patients, always complain without giving a solution!!!

- Is it true that we complain without offering a way out to all these problems?
- Are the Associations a sort of burden for the Health Care System?
- Are they an anachronism in the post modern society?
- Are they a volunteer heritage of the outdated XXth century culture?
- Are they losing and wasting their time? And do they waste the time of the their institutional counterparts?

## A chance: a change!

- So just **MOVE ON UP!**
- **We can really be a chance for the all system**, but we probably have to change something, inside our Associations and outside, in the way we confront our counterparts and we maintain our relationships.
- We can **offer solutions** because **we need them** more than anyone else in this system.

## First: to whom can we get together?

- Who are our counterparts? Who are our possible allied and cooperating subjects?
- The clinicians and the nurses.
- The Hospital Administrators.
- The Drugs Companies.
- The Local or Regional Institutions.
- The Central National Governments.
- The European Community.
- T.I.F., ENERCA and all other Associations or Federations of chronic pathologies patients.

## Second: what we want.

- The Associations of patients have, at last, a really simple goal: **to promote health for the patients and a better life to everybody**.
- To get this is quite simple: there are just a few sub-topics like better therapies, a simple way to get them, good diagnosis, the fewest possible of bureaucracy complications, a good relation with our clinicians, the cheapest cost as possible to get the drugs and the therapies.

## Third: how to get together and why?

- Who really should care for our partnership?
- And why our partnership should be interesting for them?
- What can we really bring them as a gift?
- What can we do to demonstrate them our power and our function for this system?
- But also, **they have to change something when they approach us!!!** Stop treating us as a problem, we don't allow them!

## A new deal: the patient as a partner!!!

- Let's try to start our analysis, it can be interesting and somehow surprisingly ....THRILLING

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- The first subjects to realize our potentiality as partner, no matter, have been the Pharma Companies.
- Why? What do they get about our possible role that the other have not discovered yet?
- Is it a scandal? Are we just marionettes in their skilled hands?
- Or does it depend from ourselves?
- Discussion...

#### The Pharma Companies and the Patient as a Partner

- The Companies realized that we can support them in convincing the Hospital Managers, the Clinicians, the local and national Authorities, that one drug can be better than another one, if it fits our needs, and we can struggle for that, if we are convinced. Is it a scandal?
- The scandal should occur if we would have sold our activities for cash, if we were not convinced.
- But normally, our activities should be governed by our real needs, which are, as previously described, our health.
- We, in Thalassemia world, have demonstrated that we can struggle for a drug, if we feel that that drug is essential for us: the Rare Drugs legislation, the legislation for the so called *Orphan Drugs* in Europe, have been discovered after our struggle for the recognition of an iron chelator drug.
- In Italy the *compassionate use* of a drug was born in the same period, through the same struggle.
- So, the Pharma Companies are right in seeing us as a potential partner. And we teach us that we can be powerful. **It's up to us not being manipulated.** We are strong, we not necessarily should become strong and stupid!
- But this confirms that we can be partner for the Companies, and we must admit that they sometimes offer us good programs and events to co-operate and develop our skills.
- Moreover, we need their work to develop new and better drugs, in many aspects of our complex co-morbidities.
- In our experience as UNITED, the Italian National Federation of Thalassemia and Sickle Cell patients Associations, we have never refused to co-operate with interesting programs of none of the Companies, although, until now, we have just received an help to organize the first International Scientific Congress.
- But we are proud to say that we try to stimulate continuously their help to promote new and better drugs, and we offer them **our feedback** on their therapies, because this is important for us as patients, not only for them as Companies.
- So, what is the lesson we got from our relationship with the drug Companies?
- We can be powerful. We can be strong.
- We can be useful for them at the same time as they are useful for us.
- We don't have to sell ourselves mandatory if we are strong enough. The relationship can be really honest, two ways.
- **Our feedback is important for them.**

#### The doctors and the patient as a partner

- Why cannot we be partner for our clinicians?
- Is there something that separate the patient from his doctor?
- Or should it be much more natural to establish a co-operation, that should also mean a **clinical alliance**?
- The patient, his doctor and the nurses, can create a very good team for the best performance of the hospital activities.
- They can ask for better conditions **together** in their relations with the Hospital Managers.
- They can discuss the best way to manage the Day Hospital activities and timetable.
- The patient can suggest new solutions to spare time, not losing the best care.
- The doctors and the nurses can suggest better behaviours to the

patients to lose less time because they know some organisation aspects that can accelerate the process, and so on.

- In our experience as UNITED, we tried to stimulate a co-operation with S.I.T.E., the Society of Thalassemia and Sickle Cell disease clinicians.
- We had many co-operation activities we can try with them: **we need their help to cure us**, to continuously ameliorate the therapies, diagnosis, day by day care, the clinical research, and many other reasons.
- We asked for their help because we want a better legislation for the **driving licence** (at the moment we have to get our driving licence renewal through a commission) and we needed a scientific paper for the Parliament initiative. And they gave it to us.
- In a meeting with our Board and the Board of S.I.T.E. we planned some activities to carry on together, and they propose us a **map of all the patients and the Centres** of cure, because the last official map is already some years old.
- It is something we also want to do, and together we can have more information, because we can get some patients they don't know where is cured, and they can get information through official Hospital channels we can probably not reach.
- We also want to be able to compare the various level of treatment the Centres offer in our Country, and try to improve the ones which are under a level we consider as at least satisfactory.
- Just at this time, we got from them an email to evaluate, before it would be released, a *letter of informed consent* for a new important trial that will start in 2015.
- We can push & press the Hospital Managers to support our clinicians in a stronger way, when they sometimes seem to forget our pathology among the rest of their activities, and this can help our doctors way of work.
- And the same at a National level in our relationship with the Ministry of Health. Our voice as National Association can produce more than the clinicians claims for help at a local level.
- So, there are many aspects of our clinical life that should get better through the co-operation and the partnership of patients and clinicians, no cost at all, spares for everyone.

#### Thal World. Our world. The actors involved.

- We already discussed about our counterparts: the clinicians and the nurses, the Hospital Administrators, the Drugs Companies, the Local or Regional Institutions, the Central National Governments, the European Community, T.I.F., ENERCA and all other Associations or Federations of chronic pathologies patients.
- Think about all of us as members a group, our group, our world.

#### Our world, our group. The actors involved.

- In each group, we know from the social studies and the communication analysis, each actor is always in a **relation of interdependence** from the other members of the group.
- It's the same in our world.
- But it's also true, as the communication analysis teaches, that we always communicate each other, also if we don't do anything.
- So, what do we communicate when we don't do anything, as Associations? Just that we don't care what the others do.
- Or when we communicate just by complaints? Just that we are not happy, sometimes that we won't be ever happy, so why should they care?
- But when **we take the situation in our hands**, when we give them a solution for our problems? We communicate that we trust them as honest counterparts, and that make them feel they can co-operate with us to find a real solution. **T.I.F. is a clear example of this attitude.**
- And also, we can transmit them a **feeling of hope** through our ideas.

**The Associations in our Country.**

- UNITED, the National Italian Federation of the Associations for Thalassaemia and Sickle Cell Disease Patients, was born just three years ago, after many years in which all our Associations in Italy were working each one separately, but without finding a common way to face all our National counterparts and needs.
- We spent a lot of time in convincing everyone that it was a priority for our aims to get together and to face our problems as a unique Group.
- Our world of Associations was really complex and split, somehow quarrelsome, but most of all, if compared with other chronic diseases, the Associations in Thalassaemia and Sickle Cell Disease **were ineffective to reach their goals**, although the number of patients is not so little in our Country.
- So, the **lack of unity brought a lack of efficacy**.
- UNITED is still fighting to root itself in our world, we have to increase the number of supporters Associations, although we already represent the most of the patients. But it's an endless fight until we get some important results.

**The Patient as a Partner.**

- UNITED have in these years co-operated with many of the actors involved in our world, always giving them the patient's view of the problem, and always offering them ideas to solve the troubles, in a peculiar positive way.
- With the doctors and nurses locally, at a regional level, creating new Hub & Spoke Systems for the Centres, supporting research plans with our activity of pressure on the Institutions.
- Keeping in touch with the clinicians Societies in Italy as S.I.T.E. (the Thalassaemia clinician Society) or S.I.M.T.I. (the Transfusion clinician Society), or with International Associations as T.I.F., or networks as Enerca, we tried to spread information and cultural scientific events, which often give the chance to participants to develop important national or international relations.
- We tried to participate to the drafting of S.I.T.E.-S.I.M.T.I. Agreement on blood transfusion in Thalassaemia and Sickle Cell Disease in Italy.
- We met all the Regional Health Institutions and various personalities in the National Ministry of Health.
- We met our clinicians locally and at a national level when new therapies were released and when we wanted more guarantees for the patients.
- We never forgot in all our activities that we had to **consider the**

**costs of our requests**, and sometimes we gave the cheapest solution, because we know when something is a real need. But we never stopped asking for what we really need.

- And we always had the impression that we were offering solutions, and that our ideas were important for them.

**The Patient as a Problem? Or the Patient as a Problem Solver?**

- So, it's a long way we have to do, but the fight has to go on: we have to consolidate our structure inside to be more effective outside.
- We must go on thinking of new solutions because this situation ask for **the Patient as the Problem Solver**. This is the way we can get in relation with the Institutions and get what we want: respect for our needs, results in the level of treatment, and for all aspects of our life.

**Conclusions and suggestions.**

- George Costantinou wrote in *A Guide to establishing a no-profit patient support Organisation*: "I want to be an active member of the society I live in! Respect me, respect my time and respect my life!"
- And Shobha Tuli: "Ultimately, we have knowledge, and we have hope. Let us commit ourselves to spreading the knowledge we have about Thalassaemia, along with the hope that our future will be bright".
- The Patient can be a Partner for the Clinicians, the Pharma Companies, the Institutions.
- The relation to be productive need a change from ourselves. Knowledge and expertise are our goals, to be able to counsel solutions to new scenery. But also a different approach from our counterparts. We need to start a relation of EQUALITY, in the diversity of roles.
- We can not accept a relation of inequality, in which they act as we were just problems.

**Take home message.**

- **The Patient can be the Problem Solver.**
- The Patient must **get the knowledge**, spread the knowledge, learn the laws, learn the techniques, know the therapies, the real situation of the other patients to be an effective Partner. **And take the LEAD**. And save and develop the HOPE for a better future, trying to communicate all this to HIS WORLD.
- This is our goals, to help all the system in these days of uncertainty, but also of great expectations for our future.