

From Empowerment for Patient Organisations to Empowered Patient Organisations

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Introduction

The TREAT-NMD project is a network for people with neuromuscular diseases and professionals working in the field. It aims to advance diagnosis and care and develop new treatments for the benefit of patients and families, working closely with scientists, healthcare professionals, the pharmaceutical industry and patient groups around the world. TREAT-NMD does have projects that are important for patients, patient organisations, physicians, researchers and industry to know about. These projects are important tools to accelerate treatment for neuromuscular diseases. The support from patient organisations is needed to make these projects work optimal and reach the joint goal of the TREAT-NMD project. (see *TREAT-NMD website: www.treat-nmd.eu*)

The need to empower patients and patient's organisations within the TREAT-NMD project

The people TREAT-NMD works for are those involved with neuromuscular diseases. Most people with a neuromuscular disease are mild to severely disabled by the disease. The disabilities people with neuromuscular diseases like Spinal Muscular Atrophy, Duchenne Muscular Dystrophy, Friedreich's Ataxia, Pompe Disease etc. can be confronted with include: impaired mobility (wheelchair, walking aids or very restricted walking distances), impaired breathing (invasive or non-invasive ventilation is required), limited arm or hand function, decreased ability to eat (leading to malnutrition and requiring nasal or gastrostomy - tube feeding), being depended on full time care, impaired speech and sometimes - like detected in some infant Pompe patients - impaired hearing.

Getting treatment for people with neuromuscular diseases is a very important issue for society, physicians, researchers, industry and of course patients with a neuromuscular disease themselves. However we must also think of what happens to a patient when a treatment has been found. The recent therapy to treat patients with Pompe disease can be used as a good example and model for other neuromuscular diseases. In Pompe disease now an enzyme replacement therapy is available that in many Pompe patients is beneficiary. Having a treatment available does mean a lot to Pompe patients and their families, but many experienced that the already gained disability caused by Pompe disease can't be eliminated. This means that having access to the right care, rehabilitation, physical therapy, speech therapy, equipment, education, work, housing and society in general becomes even more important. Many Pompe patients may live longer than before they were able to receive treatment, even when they are already severely disabled. In Duchenne Muscular Dystrophy also a lot has happened the past 20 years. Treatments with steroids and ventilation combined with the expectation that patients with Duchenne Muscular Dystrophy can lead a good life have resulted in a general care that has increased the number of patients with Duchenne Muscular Dystrophy considerably in some countries. A study in Denmark revealed that the number of patients with Duchenne Muscular Dystrophy increased from 80 patients in 1987 to 200 patients in 2009 (*Rahbek J. e.a., 2005, 17-28*). For the (near) future it is expected that the incidence of the various disorders will be constant, but the prevalence will increase considerably, as the life span is expected to increase while the degree of disability will decrease. This, in turn, will make it necessary to broaden the empowerment concept to issues of the normal daily life. Empowerment, however, is not only an issue outside of the direct medical care setting, it is also important within the medical care setting. Physicians, scientists and care takers too must learn that patients do have a lot of knowledge and experience they can learn from and use in their studies and research. In some situations it may only be a matter of asking the right questions to patients, so the good and important answers can be given.

Now treatment for Pompe patients is a fact and the care of Duchenne patients has clearly improved, thanks to the effort, hard work and a lot of financial support by many, it is important that those patients also are given a life by our societies. To be able to live their lives it's

important that their patient organisations and patient representatives are empowered enough to fight for the needs and rights of people with a neuromuscular disease. After treatment a new challenge begins. After all the fight for life isn't over when treatment has been developed. Treatment must be approved by authorities and reimbursed by governments or insurance companies. This looks straight forward, but it isn't. To make this all happen patients and patient organisations must know how to get their available treatments reimbursed and accessible for all patients. When treatment is available, reimbursement arranged and care (ventilation, G-tube feeding, equipment) has improved so that people with a neuromuscular disease will live longer, the next step will be participating in society and that is not easy when one has a disability caused by a neuromuscular disease or any other cause.

The position of disabled people in the world

Disabled people are often highly discriminated when it comes to access of education, employment, health etc. The groups most affected are disabled women and children and especially intellectually disabled people. Often disability is seen as a medical issue instead of a human right issue. The emphasis should be on inclusion rather than on disability.

Marginalized people, like many people with a disability, who have no opportunities for self-sufficiency become, at a minimum, dependent on charity or welfare. They lose their self-confidence because they cannot be fully self-supporting. The opportunities denied to them also deprive them of the pride of accomplishment which others, who have those opportunities, can develop for themselves. This in turn can lead to psychological, social and even mental health problems. A good self-image and a good knowledge of one's disease and/or disability – disability awareness – is an important precondition for the ability of people with disabilities to grow, both individually and as a group. Strengthening individuals must be clearly user-driven. The people themselves must formulate their needs and the way in which those needs can be provided for. In many situations different measures to strengthen the individual are necessary for an organisation to be able to grow in strength or increase its internal democracy. Some examples for strengthening individuals to empower patient organisations are: income generation schemes, training and educations, rehabilitation, self help groups, sign language etc. Some examples of capacity building for patient organisations are: organisation management, communication skills, leadership training etc. (*Dutch Coalition on Disability and Development, 2005, 5-10*). Changing and developing the structure of society that right now is dominated by the able bodied 'healthy' people is important for everyone involved with disabilities and also society itself. Often city planners, architects, employers, medical equipment designers, industrial designers etc. don't have disabled people and their needs in their mindset. They simply don't think about it and therefore don't consider the needs of disabled people regarding accessibility of buildings, public space (museums, fun parks), transportation (why can engineers not design and built a plane accessible for wheelchair users, so all the fuss to board and un board isn't necessary anymore?), jobs, medical equipment (MRI scans, CT scans, DEXA scans) etc. It's crucial that patient organisations and disability organisations are key players in all lobbying activities. During the Patient Voice / Patient Communication Working Group Meeting at April 17 2009 the word 'involvement' of patients has been used a lot. But according to the congregated patient groups, the word 'involvement' is not the correct word...it is as Francis P. Crawley stated 'about participation in decision making that is important. Patient organisations want to be an equal partner!' (*Report TREAT-NMD Patient Voice / Patient Communication Working Group Meeting, 2009, 6*)

The differences between the regions

Of course there are differences in the several countries in the world regarding the position of people with a disability. In the more developed world, where most often also more money is available, the position of people with a disability is better than for those living in the developmental world. There are also differences between countries in Europe. In Eastern European countries many people still think from a centralistic approach, an approach that still can be seen too in Western European countries, but that now slowly declines because disabled people don't want to be excluded anymore. Children with disabilities in the Netherlands for example should be allowed to normal schools, though with some resistance from (able bodied and healthy) school boards. A disabled child sometimes requires some

extra attention and/or help for which extra financial budget can be provided, but that of course also needs extra effort from the teaching staff. Luckily some schools do allow disabled children without trouble, but others still do not. However this development is not happening in all countries yet. An example is the practice of setting up day care centres for children with disabilities in Bulgaria (and also on a larger scale across the Balkans), which is frequently justified by the needs of the parents. Parents need jobs to support their families, they need time for themselves and they need medical and psychological care for their disabled child. However this practice is violating the human rights of the children to study and socialize with their non-disabled peers. Disabled children are being isolated from their peers and don't learn to live in society and society in turn will not learn to live with disabled people. Education in those centres is often of poor quality (this is not only for Eastern Europe, but can also be seen in Western Europe) and the development of social skills in a natural environment is missing. These centres don't prepare disabled children for adulthood where everyone must have developed skills to compete with others. Often these children move from such a children's centre to a sheltered house (*Dutch Coalition on Disability and Development, 2005, 23*). Another issue that needs to be considered is that some countries do know a strict hierarchy regarding professionals and non-professionals and in other countries it can be more relaxed. This hierarchy topic can be an issue when it comes to physicians or scientists dealing with patients, who don't have the same scientific background or the other way around, as some patients also must learn to work on equal level, but with different knowledge and skills, with physicians and scientists.

Empowerment

Empowerment is the process of obtaining the basic opportunities for marginalized people, either directly by those people, or through the help of non-marginalized others who share their own access to these opportunities. Empowerment also includes encouraging, and developing the skills for, self-sufficiency, with a focus on eliminating the future need for charity or welfare in the individuals of the group. This process can be difficult to start and to implement effectively, but there are many examples of empowerment projects, which have succeeded.

One empowerment strategy is to assist marginalized people to create their own non-profit organization, using the rationale that only the marginalized people, themselves, can know what 'their own' people need most, and that control of the organization by outsiders can actually help to further increase marginalization. Charitable organizations lead from outside of the community can disempower the community by increasing a dependence on charity or welfare. A non-profit organization can target strategies that cause structural changes, reducing the need for ongoing dependence. The Red Cross, for example, can focus on improving the health of indigenous people, but does not have authority in its charter to install water-delivery and purification systems, even though the lack of such a system profoundly, directly and negatively impacts health. A non-profit organisation composed of indigenous people themselves, however, could insure their own organization does have such authority and could set their own agendas, make their own plans, seek the needed resources, do as much of the work as they can, and take responsibility - and credit - for the success of their projects (or the consequences, should they fail).

The process of empowerment is the process, which enables one to gain power, authority and influence over others, institutions or society. Empowerment is probably the totality of the following or similar capabilities:

- Having decision-making power of one's own
- Having access to information and resources for taking proper decision
- Having a range of options from which you can make choices
- Ability to exercise assertiveness in collective decision making
- Having positive thinking on the ability to make change
- Ability to learn skills for improving one's personal or group power.
- Ability to change others' perceptions by democratic means.
- Involving in the growth process and changes that is never ending and self-initiated
- Increasing one's positive self-image and overcoming stigma

- Increasing one's ability in discreet thinking to sort out right and wrong

In short, empowerment is the process that allows one to gain the knowledge, skill-sets and attitude needed to cope with the changing world and the circumstances in which one lives. Empowerment is, therefore a process or journey towards assisting someone to live a life of her/his choice. It cannot be achieved in the split of a second and is very difficult and expensive. Therefore the process of empowerment needs enough resources for it to be achieved. When one has been able to gain this empowerment one can gain autonomy in all areas of ones life. The concept of autonomy can be described as authority over ones own life and body, the ability to make own choices and to influence processes of social change (Boesveld e.a., 1987, 16 – 17). Autonomy in itself is a complex concept that can be used from different perspectives and levels. It is important to understand this before autonomy is being used as a way to analyse the position of (disabled) people. In an essay of Maryze Schoneveld van der Linde an overview on the concept of autonomy is given (Schoneveld van der Linde, 1995: 16 – 19). The concept autonomy is a tool that can 'measure' how empowered someone is. This concept of autonomy can be used for individuals and groups (*José van Santen, 1993, 1 – 11*).

How can patient organisations be empowered?

Empower patient organisation leaders with management and leadership skills. In many countries the current education system is grounded in a system that segregates the disabled and/or sick person. In many countries existing special schools have limited capacity and this results in the exclusion of the vast majority of students with disabilities from accessing education. Many disabled people have no access to higher and tertiary education. This has resulted in situations where patient organisations, especially in developing countries, are led and managed by unskilled people that consequently led to a collapse of an organisation or a badly managed organisation. An important aspect of patient organisation empowerment is that at least the patient leaders do have the ability to speak and understand the English language. Being able to understand English gives access to information (on the Internet), and improves communication to people from other countries that enables people to cooperate on International level. Education is the bread of life, "Teach someone to fish and (s)he will never beg".

Disseminate information to patient organisations. There is a need to make sure that patients and patient organisations actually receive information about developments in their disease, medicines, treatments, rehabilitation and other available options. Information is one of the major tools in empowerment.

Promote the concept of independent living in countries where it's not available. 'Independent living' is a philosophy for self-determination, equal opportunity and self-respect. It is a demand for the same choices and control in our every-day lives that healthy and non-disabled people take for granted. This means growing up in families, attending neighbourhood schools, using the same bus as our neighbours (the name 'public transport' is not correct as in many countries this type of transport is not public at all since wheelchair users, people with walking difficulties or people with prams can't access busses at all times and only have limited access to trains), working in jobs that match educational achievement and ability and start families of ones own. Patients and disabled people also want to be in charge of their lives, to think and speak for themselves.

Introducing rights-based programmes is important, because disability is not rare; it affects 10% to 20% of a country's population, a percentage that is expected to increase because of poor health care and poor nutrition early in life in developmental countries, improved health care of those with a chronic disease and better medical treatments that keep people alive, growing elderly populations and violent civil conflicts. For disabled people to be able to advocate for their lives and improvement in services, they must be aware of their rights. (*Dutch Coalition on Disability and Development, 2005, 21*).

The mutual benefit of empowerment

Empowerment is not just a tool for patient organisations and patients themselves, but also for society. In a publication on patient empowerment in diabetes patients it is stated that patient empowerment is an effective approach to develop educational interventions for addressing the psychological aspects of living with diabetes. In a randomized controlled trial one group of diabetes patients participated in a six-session empowerment program and the other group was assigned to a waiting list. Six weeks after the program, both groups provided follow-up data. The results were that the intervention group showed gains of the control group on 4 of the 8 self-efficacy subscales and 2 of the 5 attitude subscales. The intervention group also showed a significant reduction in glycated haemoglobin level (*R.M. Anderson e.a. Diabetes Care July 1995 vol. 18 no. 7 943-949*). The benefit for society is that when patients do feel well and are able to manage their lives good they will probably require less care or psychological support. Also an empowered patient population will encourage health care professionals to improve their service. During their study physicians and nurses are taught to work in a demand-driven health care and to create a good relationship with the patient so they will feel better and taken seriously. More and more patients are involved in the development of protocols. Even science must nowadays answer questions that come from patients and society in general, because people ask questions and want to know what is going on (*Denijs Guijt and Pieter van Megchelen, ZonMw Mediator 1 – 2005*). While reading the several articles on empowerment of disabled people and patient empowerment it can be learned that the areas of implementation do vary. When one talks about empowerment of disabled people it's more on general empowerment in society and the ability to fully participate. Patient empowerment however seems to be used within the health care system specifically and refers to six domains like knowledge, access to health care, advocacy, decision making, health status/outcomes, and literacy (*S. Loukanova and J. Bridges, June 2006*). We should try to combine all the aspects of empowerment. A patient is any person who receives medical attention, care, or treatment, but also someone who is involved in all aspects of society. 'Patients' with a neuromuscular disease are a patient when they are receiving treatment or care, but also are disabled people in society where they need to have a job, study, house etc. Wouter Boon writes in his thesis 'Demanding Dynamics – Demand articulation of intermediary organisations in emerging pharmaceutical innovation' that the VSN (Dutch Association of Neuromuscular Diseases) can be characterised as a representative user organisation and one of the few Dutch patient organisations that is engaged in research on diseases and therapies in early stages of development. While referring to the VSN he writes: 'Patient organisations should take the lead in these disease areas because other players would be less willing to do so. Patients were regarded as the most important stakeholders. "And even on a difficult domain, such as scientific research, patient organisations can achieve important results with good policy, strategic action, and purposeful cooperation." The patient organisations can serve as "lubricating oil in the difficult relationship between industry and science". Moreover, patients themselves are highly knowledgeable about their disease, and that knowledge could be used by companies and scientists.' (*Wouter Boon, 2008, 100-101*).

Conclusion

Empowerment and Patient empowerment are tools to work with within the TREAT-NMD project. The patient groups TREAT-NMD works for are those who are affected by neuromuscular diseases that often lead to severe disabilities. These patient groups should get the tools to get information on issues like developments on specific diseases and treatments. They also need to know what issues are involved to get reimbursement for treatment, cure and care. Besides these important topics patient organisations and patients must be able to live their live in a way they can choose for themselves. To be able to do that they must be given the tools to do so. Empowerment itself is not only a benefit for patient organisations and patients, but also can be one for physicians, scientists or even society in general. Well informed patients are often more compliant to treatments. Patients can give insights in health issues from a different perspective that can be beneficial for research, clinical trials or treatments. Empowered people with disabilities will participate in society more actively and for example can have a paid job and pay tax. These are all examples of the two sides of the coin regarding empowerment.

Empowerment workshops seem to be a good option to provide patients and patient organisations with tools how to deal with all kinds of aspects in their lives. To develop and organise these workshops experts from different areas should be invited like patients and patient organisations themselves, experts on disability and disease, ethicists, psychologists etc.

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