



Patients to Help Doctors

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Sometimes it is not enough for doctors to merely diagnose and treat their patients. New patients especially feel that their physicians should take time to inform them about the disease they are being treated for and the consequences. The patients have the right to informed consent, the right to information concerning their own health and the right to access to their medical records [1]. Although thyroid diseases are common [2], most patients (as well as the general public) know very little when they are newly diagnosed. General information many times is lacking. Patient Organizations can assist doctors with this.

In the Seventies and Eighties, patients in Europe and North America started to get organized and to change things. Of course, information then was limited (before Dr. Google and Internet). Furthermore, patients didn't have much say in the way they were being treated. Many times, they were not aware on how research was being conducted. Some hospitals had brochures on certain diseases, but seldom about what the disease actually meant for the patient's life. Information was incomplete.

Benefits of patient organizations

Doctors usually have an average of 7 minutes [3] for each visit with their patients. Is this why they only listen 11 seconds to each patient? [4]

In these 7 minutes the doctor has to listen to the patient, palpate the patient, ask questions, make a diagnosis, decide on the next step and then inform the patient. It is very difficult to answer in these 7 minutes all the questions that a patient might have about the diagnosis. And, here the importance of patient organizations steps in!

Doctors can benefit from Patient Organizations through their brochures with lay level general information on the disease. The patient can get in contact with the Patient Organization to ask general questions that many people have. This allows the patient to be an "informed patient" and a more equal partner with the doctor. The patient can get in contact with the Patient Organization to ask the general questions about the disease and the life with the disease that they have. That saves the doctor time in their second consult with the patient, that can be used for patient specific information.

Reliable Patient Organizations provide patients with evidence based information and they can warn for misinformation from unreliable sources propagating unproven remedies by quacks.

Scientific and therapeutic activities

For a number of years, patient groups have been involved in medical guidelines and in scientific activities. The concept of the 'expert patient' or the 'expert by experience' has been developed. The goal of the expert patient is to contribute to research and healthcare using his or her unique expertise - as someone who has the shared experience with a disease and the healthcare surrounding that. The evidence to show its impact on healthcare and scientific research is growing all the time. Many patient organizations have developed processes and methodologies to ensure their members are ready for project groups for research and clinical trials, and to ensure that patients are available to participate where appropriate. Many patient organizations from around the world have gathered to help others as experts in their own disease.

Research

Patient Organizations are also playing an increasingly important role in funding research. Together with universities and the pharmaceutical industry, more research is facilitated and there is more influence on where money is spent. In the Nineties, Patient Organizations began involving patients in research and health policy [5]. They set up special advisory councils consisting of patients with the disease. These councils help develop standards of care, guidelines for care and translations of these guidelines into layman's terms, as well as setting research priorities, developing criteria to evaluate research from the patient's perspective, implementing research policies, evaluating research proposals in annual subsidy rounds and monitoring of current research projects [6].

Public and patient involvement in projects has become an essential requirement for obtaining EU funding. A good example in the thyroid arena is a project called 'TRUST [7] (Thyroid Hormone Therapy for Older Adults with Subclinical Hypothyroidism)', a project in which Thyroid Federation International has partnered with universities in the UK, Ireland, Switzerland and the Netherlands providing the means for public dissemination of information about the project. Patient representatives have played a key role in the main stages of the TRUST project: in the development and formula-

tion of the proposal itself, in the Ethics Committee and the Safety Board, and in the content and tone of the website. The involved patients were also able to give their advice to the project as a whole when there were difficulties with the recruitment rate of subjects for the project.

Thyroid patient organizations

The Thyroid Foundation of Canada was founded in 1980 by Diana Meltzer Abramsky CM, BA in Kingston, Ontario, Canada [8]. Diana wanted to help the many patients suffering from thyroid disease as she had done. With the assistance of Dr. Jack Wall she began the very first thyroid foundation in the world. A research fund was set up and educational material developed for patients on a wide range of thyroid topics.

In the following years thyroid Patient Organizations were started in several countries and six thyroid Patient Organizations from Canada, USA, Germany, Italy and United Kingdom were represented at the 1995 inaugural meeting of Thyroid Federation International (TFI). Soon thereafter, The Netherlands, Australia, Sweden and Denmark joined as well [9].

Now that 25 years have passed, the mission of TFI hasn't changed much: it aims to work for the benefit of those affected by thyroid disorders throughout the world [10]. It provides information and moral support to those affected and promotes education and research related to thyroid disorders.

TFI today has nearly 40 members from all continents. Most of the members are patient lead organizations, and there are also some national thyroid associations that provide evidence-based information to patients [11]. The patient lead organizations work closely with the medical professions to promote awareness and understanding of these disorders and their complications. TFI has a Medical Advisory Panel that invited or uninvited advises the board on medical issues and keep track on the quality of the information [12].

Thyroid awareness

In 2007, TFI introduced World Thyroid Day and chose May 25th. In 2009 they initiated an International Thyroid Awareness Week that followed the date of May 25th for an entire week. The ITAW is celebrated with patient meetings, lectures, tests on thyroid diseases, radio and television interviews in approximately 200 countries throughout the world [13].

Conclusion

Patient Organizations can make life easier for doctors by creating a more equal relationship between the patient and the doctor and with guidelines that are connected with the reality of life with the disease.

Thyroid Federation International in Budapest 2019.



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