



Patient Rights in northern part of Cyprus and UPRA “The story of a pioneering organisation”

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Universal Patient Rights Association (UPRA) was founded in 2002 in northern part of Cyprus in order to raise awareness about patients' rights, advocate for enactment of the EU Charter of Patients' Rights in the country. Our organisation is directly supported by North Cyprus Thalassaemia Association, Association for Persons with Orthopaedic Disability and Help Those with Cancer. These CSOs are three of most prominent health organisations within the Turkish Cypriot Community.

When UPRA was founded there was no specific law, legislation or charter for the protection of patients' rights in North Cyprus and unfortunately the situation remains the same, as the draft law prepared by UPRA and which was submitted by the Health Administration in 2008 became obsolete with changing governments. Therefore, UPRA has recently intensified its efforts in creating awareness raising campaigns about patients' rights so that the general public begins to demand their rights from the authorities; and it is also persistent about being involved in policy/decision making processes and implementation of the health policies. For these reasons, UPRA recently became a member of complaints committee representing the patients, under the auspices of Health Administration.

In that sense, UPRA serves as the only organisation in northern Cyprus whose mission is based on patients' rights and which is offering support for patients and their relatives in their struggle with violation of their rights.

UPRA's scope of work is not limited to advocacy work and awareness rising but it also involves capacity building on patients' rights through tailor-made trainings available for other CSOs as well as individual participants.

Our mission

The mission of UPRA is underpinned by the fundamental principles of the Universal Declaration of Human Rights and the “14 Patient Rights”, agreed within The Charter of Fundamental Rights of the European Union, and states that everyone within the Turkish Cypriot Community deserves the:

- i) Right to have access and receive the health care worthy of human dignity from the health institutions and health sector service providers;
- ii) Be able to take advantage and benefit from the “Patients' Rights”;
- iii) Be able to seek protection and remedy against human rights violations and patients' rights violations;
- iv) Have access to the necessary effective legal protection and remedies as and when necessary;
- v) Be involved in the planning of patient rights policies and practices, their evaluation, implementation and supervision, equal health services, ensuring high quality and effective presentation.

Every patient is marginalised when their rights are violated

Within its scope of work UPRA emphasizes the importance of amplifying the voice of those patients whose voices are unheard or suppressed either simply by lack of awareness among general public or lack of legislation protecting their rights.

Every patient feels the sense of being marginalised when his normal life is interrupted by illness or his chronic condition prevents him from feeling accepted in “normal” life. Aside from serving as the only CSO working on patient rights, UPRA makes extra effort to make sure that the patients who are further marginalised (mental health patients, persons with disabilities as well as bedridden patients, refugees, patients with HIV etc”) feel that they are not alone and that there is an organisation who will fight for their rights to be recognised and protected.

Patient rights are continuously violated

When there is lack of legislation protecting their rights patients are left with very few options. Turkish Cypriot community is a small community and nepotism is a widespread phenomenon within the healthcare system as well as in other fields of life. So, when a patient's right is violated, it is based on who they know within the authorities to defend their right. This creates a systematic violation of citizens' human rights, as every citizen have the right to be treated equally.

Therefore UPRA also focuses on reaching out to patients in rural areas who have decreased access to healthcare services and generally are less aware of their rights. Therefore, in the framework of the "Patient's Voice" project it is implementing; UPRA receives signals/complaints from patients across the country.

Lobbying & Policy engagement

UPRA's awareness raising campaigns have been on-going especially after the inauguration of the Patient's Voice project. However, UPRA's work is not limited to advocacy and capacity building. UPRA is also very dedicated to its lobbying work for patients' rights and has identified the policy makers who can further advocacy work within the decision making mechanisms. In addition to this, UPRA is an active member of several policy making committees working on new healthcare/national health insurance policies.

Facts about current healthcare system and legal framework in north Cyprus

- Public healthcare is free of charge for public servants and their families, people with insufficient income, people with disability and chronic diseases at the public hospitals.
- Private sector workers pay a fee for Social Insurance. This lump sum goes directly to the General Budget.
- After opening of the borders in 2003, Turkish Cypriots who have the Republic of Cyprus nationality had free access to the Health Care services in Republic of Cyprus.

After the financial and economic crisis in 2012-2013, due to not paying National Insurance in the Republic of Cyprus, Turkish Cypriots were exempted from the free Healthcare System, except for people with cancer whose treatment is still ongoing. As a result of this legal deficiency, there are various problems in compensation of the losses and protection of the patients' rights in northern part of Cyprus.

With regard to patients' rights legislation, there are two parallel common sources;

- * 6/2009 Public Health Workers Law
- * Cyprus Turkish Medical Association's «Medical Professionals Ethics Charter»

There are certain provisions that protect patients' rights. Those two legal regulations contains only 5 recognized rights; including:

1. Right of Access to adequate services
2. Right to Information
3. Right to Privacy and Confidentiality
4. Right to Consent
5. Right to Free Choice

The legislative background in force is insufficient in terms of protection of rights. This reduces confidence in the health system.

Due to lack of the law directly related to patient rights, there are many difficulties encountered in the compensation of the losses of the patient. Therefore Court tries to solve the claims in the general principles of the current legal framework.

On the other hand, the presence of a direct law alone will not be enough in terms of protection of rights .

As long as patients' rights did not achieve a holistic approach, the required standard of healthcare services could not be provided.

Lack of collaboration between private and public health care when public health care equipment and medicine fall short restrict the patients choice to the medical staff , the hospital and to treatment

- Long waiting lists and insufficient time spared for patients
- Providing patients with insufficient information
- Negative prejudice and reactions of the staff, professional misconduct
- Lack of awareness of both patients' and service providers about patients' rights
- Incautious registration of patient records
- Staff and health care providers not complying with informed consent procedures
- Minimal respect to patient confidentiality and privacy
- Lack of a comprehensive patients' rights legislative framework
- Lack of the right to choose health care providers
- Insufficient monitoring by the Health Administration in Turkish Cypriot Community

Collaboration

Currently UPRA is working at various levels including empowering other health organisations via networking. For that reason UPRA initiated the establishment of Health Associations Platform in February 2016. Ten health organisations are members of the platform and they are active in raising the voice of patients across the country. The Platform was recently invited to meet with the Authority of Health and give their recommendations for the new state hospital which will be built in 2017.

UPRA has drafted its recommendations which were specifically right-oriented. One of the recommendations of UPRA was the establishment of a Tribunal for Patients' Rights under the auspices of the hospital. This idea was inspired by the study visit UPRA carried out in Rome in partnership of Active Citizenship Network.

Steps forward...

In the future UPRA will continue to strengthen its collaboration with Active Citizen Network and through ACN it aims to reach out to other health related organisations across Europe.

- UPRA aims to develop the complaint mechanism within the Association via utilising the knowledge the delegation gathered during Study Tour and with the support of ACN.
- UPRA aims to support the development process of the complaint mechanism at the hospitals.
- UPRA aims to prepare "patients' rights" monitoring reports about the disadvantaged citizens.
- UPRA will play a more active role in participating European Campaigns such as EU Patients Rights and/or EU Cross Border Healthcare
- UPRA will be more active in Cyprus across the divide through its participation to the peace process.



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