The Italian Rare Cancer Network

La rete italiana dei tumori rari

Rete Tumori Rari

Italy has a population of over 60 million. The total number of new cancer cases each year is about 360,000; of these, 89,000 – more than 25% – are rare. If the group of rare cancers is split up into all paediatric cancer cases, all haematological cancers except lymphomas (which are not rare, unless they are further split into subgroups), and rare adult solid cancers, the latter account for about 60,000 new cases each year. The Italian health system is region-based, with 20 regions. The new cases of rare adult solid cancers in each region range from slightly more than 100 to almost 10,000, i.e. there is a difference by a factor of 100 in the number of new cases seen region by region. The smallest region parallels a small city, the largest ones are tantamount to some European countries.

It is useful to single out rare adult solid cancers because Italian paediatric cancer patients have a number of centres available that are highly specialised in their care and have pooled efforts effectively over the last decades. Collaboration between these centres has led to "large" clinical studies, in a research context which has always been marked by a kind of overlap between research and healthcare. This means that quality of care for paediatric cancer is assured by a system of dedicated centres of reference that are used to collaborating with each other. A similar situation occurs for haematological neoplasms, since clinical haematology has always had a strong academic tradition in Italy. Again, there are several high-level reference centres, which, likewise, have been able to collaborate on clinical research in recent years. Unfortunately, the same cannot be said for rare adult solid cancers, at least if one considers them collectively, even though there are reference centres for each of the rare cancer "families". Although these institutions, too, have developed collaborations for research purposes, each group of rare cancers has its own research network and we lack a framework accommodating all of them to reach critical mass. Even more importantly, these efforts have not affected healthcare.

This is why, in 1997, the Rete Tumori Rari (Italian Rare Cancer Network) was set up, with the aim of covering rare adult solid cancers. The overall number of this type of cancers has been mentioned above, and this AIRTUM monograph provides detailed figures about them. Due to the main clinical interest of the coordinating group at the Fondazione IRCCS Istituto Nazionale Tumori of Milan, sarcomas were the Network's first and main focus, but over the years other groups of rare adult solid cancers have been incorporated. The core work of the Italian Rare Cancer Network is to share clinical cases between distant institutions, namely between a cancer facility handling a rare cancer case and a centre of reference specialising in treatment of that cancer. This happens at the national level, given the numbers reported by the AIRTUM monograph, which clearly show that in most regions the number of cases for each group of rare cancers is definitely low, too low to allow development of centres of expertise. It goes without saying that this results in a significant degree of health migration linked to rare cancers. This occurs despite the fact that the Italian healthcare system has high-quality cancer facilities spread across the entire country, which would certainly be able to handle rare cancer cases, if they were properly connected with centres of reference. This was the idea which led to the creation of the Italian Rare Cancer Network several years ago and which has proved to work effectively in a number of cases which currently averages one thousand each year. Of course, with about 60,000 new rare adult solid cancers each year in Italy, the Network would have a tangible impact on a population basis only if this number could be increased by a factor of 10. Indeed, several cancer facilities regularly sharing cases over the Network have been able in a way to specialise on rare adult solid cancers, in the sense that they are able to deal with some rare cancer cases by actively sharing information with centres of reference. They cannot develop the expertise of a reference centre, but have developed the ability to interact with reference centres effectively.

The Italian Rare Cancer Network is a bottom-up effort that, as such, has proved to be effective on thousands of individual patients. The challenge is now to make it grow to reach the numbers required to exert a population impact, first by covering most rare adult solid cancer groups and secondly by reaching out to a higher number of patients in each region. The first aim is currently being pursued by increasing the reference centres available in the Network, the second by stepping up the Network's organisational model, in collaboration with the Italian Health Ministry and the Conference of Regions. This is a work in progress, which involved incorporation of the Network into the national Healthcare objectives in 2012, with the goal to eventually incorporate it into the National Healthcare System. The main challenge is that the transformation of a bottom-up process into a framework endorsed by the national and regional healthcare authorities naturally implies an active transfer of resources, primarily to the facilities providing their expertise, as well as, to a lesser extent, the institutions requesting teleconsultation. A health research project will try to formally assess the Network's model, including its economic aspects and its current and potential impact on the healthcare system, while concomitantly improving it. At the same time, a working group at the Italian Ministry of Health, including representatives of each region, will try to work out the best ways to finally incorporate the Italian Rare Cancer Network into the National Health System, with the goal of improving the effectiveness of rare cancer care in Italy on a population basis and significantly reduce healthcare migration.