SICO Defining criteria to build a national excellence network

Definire i criteri per costruire una rete nazionale di eccellenza

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Surgery is the mainstay of therapy in solid rare cancer care. RARECAREnet project data have shown that 65% of adult solid rare tumours (which represent 60% of all rare tumours) can be treated by surgery alone, compared to 35% which require radiotherapy and 28% which can be treated with chemotherapy. If we consider the preferred first line therapeutic strategy by stage, 82% of patients with localised disease can be treated by surgery.

The great surgical challenge concerning rare tumours is the ubiquitous diffusion in the human body: for this reason a "rare cancer surgeon", i.e. a surgeon expert in all rare cancers, cannot exist. Moreover, a fair amount of rare cancers arise in "common" sites, leading the surgeon, though expert in that particular organ or district, to act as for frequent tumours, in a climate of uncertainty. The final result can be overtreatment, undertreatment or a harmful intervention which can dramatically change the patient's prognosis and quality of life.

Frequent cancers, which can be cured by surgery, are frequently treated according to validated guidelines or diagnostic-therapeutic pathways which can be in some way standardised. Guidelines have shown to improve outcomes even in some rare cancers: a continuous, repeated referral to guidelines might have a highly valuable educational impact, enhancing awareness of a standardised work-up among inexperienced clinicians. Unfortunately, guidelines covering the entire clinical pathway from diagnosis to treatment, including relevant referrals for the whole range of rare cancer families, are not always available and/or are difficult to access.

The key issue for rare tumours is a correct preoperative diagnosis and appropriate therapeutic planning within a multidisciplinary environment. The expert surgeon's role in a multidisciplinary

team is crucial, because the surgeon can assess the quality and feasibility of the planned surgical act, taking into account the biological aggressiveness of the disease, and matching the possible surgical outcome with different therapeutic alternatives.

Rare tumours require a deep knowledge of their natural history and biological characteristics. Such knowledge can be available only in centres in which high volumes of rare cancers are observed and treated. This is the only way to overcome uncertainty and develop the best possible, tailor-made treatments. One of the main obstacles to this strategy lies in the difficulty in defining accreditation criteria for centres of this kind, which focus on the peculiar aspects of rare cancers.

In Italy, the Italian Society of Surgical Oncology (SICO) is working with the main oncological scientific societies to pinpoint and define the criteria upon which a national excellence network can be built. The first step, which is currently being worked on with the Italian government, is to define a toolkit of indicators to enable:

- identification and accreditation of reference centres for rare tumours to which patients can be referred for an appropriate surgery, a second opinion concerning the pathological diagnosis, or preoperative treatment planning;
- definition of the fundamentals of a national excellence network in which reference centres act as hubs for referral, education, and knowledge, facilitating the integration of existing working groups;
- adequate empowerment and informing of patients and general practitioners, as well as primary care hospitals;
- prospective collection of data on a nationwide basis concerning quality of care and outcomes.