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## Editorial

### From Resilience to Empowerment: The Path of Childhood Cancer Survivors

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Treatment outcomes in childhood cancer patients have dramatically improved over the last 40 years, achieving a survival rate above 80%. At the same time, with increased survival the delayed effects linked both to therapies and to the psychosocial implications of the disease itself have become manifest. Those most commonly identified, but in a low percentage, are an increased incidence of organ defects, growth retardation, sterility, second malignancies, and neuropsychological and cognitive disturbances. Published reports on the late health effects and quality of life in childhood cancer survivors focus principally on current perceptions of prominent indicators like social life, education, occupation, fertility and marriage.

Recently, a number of national pediatric oncology societies have enlisted television and film industry celebrities in media campaigns that seek to debunk a common misperception, namely, the tragic story of the illness and death of a child accompanied by the usual dose of tear-jerking melodrama. The message we want to give to the general public is that leukemia and cancer can be cured. The International Society of Pediatric Oncology (SIOP) has set up a highly skilled working group made up of teenagers and young adults who have been cured. It is possible to meet them at conferences all over the world, where they participate in passionate and lively discussions, all the while displaying a very high degree of maturity and self-awareness. It is a fact that, among former cancer patients that have been cured and grown into adults, social exclusion and substance abuse are virtually non-existent. They can often be heard speaking with the confident voice of a winner, of someone who has survived the shipwreck and has reached a safe port after battling through the waves [1].

This attitude is defined as "empowerment" and represents the outcome that psycho-oncology aims to achieve. International studies on patients who have been success-

fully treated demonstrate that virtually all of them have developed into normal adults, enjoying good health (including sexuality and fertility) and showing normal cognitive, behavioral and emotional development. Indeed, they appear in no way to be any different from their peers in the general population with a similar level of education and employment [2,3].

Our Department of Pediatric Hematology and Oncology now counts over 2500 leukemia and cancer survivors, and we can assert that this sense of empowerment is firmly entrenched in the vast majority.

Prompted by a curiosity to better understand the outcomes and quality of life of a small group of long-term survivors (excluding brain cancer patients and those with physical impairments or disabilities), we sent a letter to 100 of our former patients, all of whom had undergone extensive psychological evaluation during hospitalization and follow-up assessment two years after completing therapy. The evaluation performed when inpatients had shown in most children signs of stress related to the disease, to clinical procedures and to therapy. Depression, anxiety, mistrust, fear, lack of adequate defense mechanisms was common symptoms.

Our letter asked the interviewees to write a narrative description about their health status, education, occupation, emotions, family, marriage and children, and mostly their feelings about their past disease and hospital care. Parents' occupations were also recorded in order to take into account possible confounding factors resulting from social inequalities.

The stories that we received made for some very interesting and illuminating reading, an confirmed the value of "narrative medicine" as a therapeutic tool free of constraints and limitations and adaptable to the abilities of the patient who describes his or her experience. Indeed, the narrative

medicine model provides the framework for an engaging, trusting and mutually rewarding relationship between the physician and the patient.

The 100 adults sampled for our survey were not chosen according to scientific criteria, but rather to reflect the diversity of patients who had passed through our ward. We thus contacted former patients of varying age (from 25 to 50), living in different regions of our country, and who had been treated in different decades (from 1976 to 2000) with different protocols. In a few cases we also considered those with whose families we had maintained a relationship. Only 62 accepted our invitation, while 26 declined and 12 did not answer at all. The reasons our survivors most frequently cited for refusing were because their spouses or companions were completely unaware of the disease or because they simply sought to break with their past.

The narratives we received yielded some positive surprises, which corroborate the concept that, if resilience is the art of adapting, empowerment is a process of personal growth based on increasing self-esteem and self-efficacy [4]. Empowerment is a multilevel construct that is built at an individual-psychological, an organizational and a socio-political/community level, and all three levels clearly emerged from most of our patients' stories, showing that they were fully healed of their disease. Empowerment elicits all latent resources in order to accentuate the values of

the person, such that he/she can consciously appropriate his/her potential, his/her being. This process overturns the perception of one's limits, in view of achieving results beyond all expectations.

In conclusion, this exercise shows that our group of adults cured of a childhood cancer had achieved good physical, cognitive, emotional and behavioral development and adjustment.

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