

## Expert Review of Quality of Life in Cancer Care

# Rehabilitation for children and young people surviving a brain tumor, and their transition to adult services: the main challenges

Veronica Biassoni, Maura Massimino, Maria Chiara Oprandi, Carlo Alfredo Clerici, Laura Veneroni, Claudia Corti, Elisabetta Schiavello, Filippo Spreafico & Geraldina Poggi

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sessions of individual supportive psychotherapy, the cost of which was sustained by the national health service. The treatment lasted several months, after which the patient remained in contact with his psychotherapist and had the option to have further talks on request (the frequency of which gradually decreased). During the past 3 years, the patient was in an emotional relationship with a woman of the same age for about a year, living together in her house at weekends. When the relationship ended he decided, with the help of his family, to buy a home where he could alone. He is currently satisfied with his own home and less worried.

The Pediatric Oncology Center is hardly the ideal place for receiving psychological support because, even if patients are cured, they have to return to the place where they were treated for their cancer. In this case, it was effective, however – partly because the patient already trusted his doctors, and partly because no other local public services would be able to implement the rehabilitation center's recommendations.

## 12. Expert commentary

Any professional interested in pediatric brain tumor care now has to face up to a multidisciplinary reality that is due not only to the many recent acquisitions in the field of biology (more accurate tumor risk stratification, new target drugs, technological improvements in radiotherapy methods and protocols), but also – as our paper has tried to broadly explain – to the many facets of post-tumor disabilities and their management. It is mandatory for pediatric neuro-oncologists to be aware of the pitfalls and possibilities of rehabilitation for survivors of childhood brain tumors so that they can take prompt action to organize the most appropriate rehabilitative tools and methods at their clinical unit and develop positive, in-depth, day-to-day relationships with modern and passionate rehabilitation centers.

## 13. Five-year view

Based on our more than 10 years of experience of rehabilitation for survivors of childhood brain tumors, we would like to stress the tremendous progress that has already been made in this field: thanks to advances in neurosurgery and tumor treatments, the survival rate 5 years after diagnosis is now 75%, and patient outcomes have improved too.

The main goal of rehabilitation should be to help patients retain the best possible quality of life. This can be done by providing ever better and more specific treatments. An approach that aims to minimize the toxic effects of chemo- and radiotherapy, optimize outcomes, reduce the risk of recurrence, and administer increasingly individualized and effective interventions will enable practitioners to shorten a patient's rehabilitation program. At the same time, the use of increasingly sophisticated technologies will enable exponential improvements in patients' motor and neurocognitive outcomes.

There are still open questions concerning patients' return to school or work, and their social interactions with their peers that pose considerable challenges: patients' needs in this

regard go beyond rehabilitation per se, with complex dynamics deriving from each patient's personal characteristics and the environment in which they live.

Rehabilitation protocols should be designed to help children and adolescents return to school, guiding them step-by-step, identifying the main needs of all stakeholders involved, and planning long-term clinical follow-ups to monitor patients' conditions and collect data with a view to designing increasingly effective supportive interventions.

The actions needed to help children return to school, achieve a good level of independence as they grow older, and have a role in society later are priority issues that must never be overlooked and that need to be addressed more specifically in future because their management in the past has been less than satisfactory.

## Key issues

- Survivors of brain tumors in childhood and adolescence face long-term difficulties and severe endocrinological, neurological and sensorimotor functional impairments. Psychological and neurocognitive deficits appear to be the main contributors to a poor quality of life and greatly affect their return to school or work.
- Rehabilitation for this patient population should be based on a multimodal approach. Additional support comes from technological advances and a more thorough knowledge of the brain's recovery mechanisms, which make it possible to use sophisticated equipment and devise computer-based cognitive training programs, such as Lokomat and GRAIL.
- Physical exercise greatly influences cognitive skills and psychological balance in pediatric brain tumor survivors. Instead of being discouraged, it should therefore become an integral part of rehabilitation programs for these patients.

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## Declaration of interest

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## ORCID

Maura Massimino  <http://orcid.org/0000-0002-5506-2001>

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Papers of special note have been highlighted as either of interest (•) or of considerable interest (••) to readers.