

available at www.sciencedirect.comjournal homepage: www.ejconline.com

Current Perspective

Long term survivors of childhood cancer: Cure and care The Erice Statement

Riccardo Haupt^a, John J. Spinetta^b, Irina Ban^c, Ronald D. Barr^d, Joern D. Beck^e, Julianne Byrne^f, Gabriele Calaminus^g, Eva Coenen^c, Mark Chesler^c, Giulio J. D'Angio^h, Christine Eiserⁱ, Andreas Feldges^j, Faith Gibson^k, Herwig Lackner^l, Giuseppe Masera^m, Luisa Massimoⁿ, Edina Magyarosy^o, Jacques Otten^p, Gregory Reaman^q, Maria Grazia Valsecchi^r, Anjo J.P. Veerman^s, Anthony Penn^t, Anne Thorvildsen^u, Cor van den Bos^v, Momcilo Jankovic^{m,*}, the International Berlin-Frankfurt-Münster Study Group Early and Late Toxicity Educational Committee (I-BFM-SG ELTEC)

^aEpidemiology and Biostatistics Section, Gaslini Children Hospital, Genova, Italy

^bDepartment of Psychology, San Diego State University, San Diego, CA, USA

^cInternational Confederation of Childhood Cancer Parent Organization (ICCCPO), c/o VOKK, Nieuwegein, The Netherlands

^dMcMaster University Health Sciences Centre, Hamilton, ON, Canada

^eLate Effects Surveillance System, University Hospital for Children and Adolescents, Erlangen, Germany

^fBoyne Research Institute, Drogheda, Ireland

^gDepartment of Paediatric Haematology and Oncology Children's Hospital, Heinrich Heine University Medical Centre, University of Dusseldorf, Dusseldorf, Germany

^hDepartment of Radiation Oncology, University of Pennsylvania, Philadelphia, PA, USA

ⁱDepartment of Psychology, The University of Sheffield, Sheffield, UK

^jOstschweizerisches Kinderspital, St. Gallen, Switzerland

^kUCL Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust, London, UK

^lDepartment of Paediatrics and Adolescent Medicine, Division of Paediatric Haematology/Oncology, Medical University of Graz, Graz, Austria

^mDepartment of Paediatrics, University of Milano-Bicocca, Hospital San Gerardo, Via Pergolesi 33, 20052 Monza, Italy

ⁿDepartment of Haematology and Oncology, Gaslini Children Hospital, Genova, Italy

^oHeim Pal Children Hospital, Budapest, Hungary

^pDepartment of Paediatrics, Academisch Ziekenhuis van de Vrije Universiteit, Brussels, Belgium

^qThe George Washington University, School of Medicine and Health Sciences, Washington, DC, USA

^rDepartment of Clinical Medicine, Prevention and Biotechnologies, University of Milano-Bicocca, Monza, Italy

^sVrije Universiteit Medical Centre, Amsterdam, The Netherlands

^tFrenchay Hospital, Bristol, UK

^uDepartment of Paediatrics, Rikshospitalet-radiumhospitalet Medical Clinic, Oslo, Norway

^vDepartment of Paediatric Oncology, Emma Children's Hospital / Academic Medical Center, Amsterdam, The Netherlands

ARTICLE INFO

Article history:

Received 20 March 2007

Accepted 11 April 2007

ABSTRACT

The number of subjects that have successfully completed treatment for a cancer diagnosed during childhood and are entering adulthood is increasing over time.

Members of the International Berlin-Frankfurt-Munster (I-BFM) Early and Late Toxicity Educational Committee (ELTEC) invited 45 paediatric cancer experts (representing oncolo-

* Corresponding author: Tel.: +39 39 2333513; fax: +39 39 2301646.

E-mail address: momcilo.jankovic@pediatrimonza.it (M. Jankovic).

0959-8049/\$ - see front matter © 2007 Elsevier Ltd. All rights reserved.

doi:10.1016/j.ejca.2007.04.015

Keywords:

Childhood cure
 Childhood care
 Health
 Quality of life

gists, psychologists, nurses, epidemiologists, parents, and survivors) from 13 European countries (with five additional experts from North America) to Erice, Sicily (from October 27 to 29, 2006) to discuss the circumstances in which the word 'cure' should be used when speaking about children with cancer, and when and why continuing follow-up and care may be required. The objective of the gathering was to generate from the personal and professional experience of the participants an overview statement of the group's philosophy of cure and care of survivors of childhood cancer. The ten points reflect what the group considers essential in the survivors' cure and care.

© 2007 Elsevier Ltd. All rights reserved.

1. The goal of cure and care of childhood cancer

The long-term goal of the cure and care of the child with cancer is that he/she become a resilient, fully functioning, autonomous adult with an optimal health-related quality of life, accepted in the society at the same level of his/her age peers.

2. The Statement

- 'Cure' refers to cure from the original cancer (see Note below), regardless of any potential for, or presence of, remaining disabilities or side effects of treatment. These side effects are a separate issue needing tailored long-term follow-up based upon subject-specific and treatment-related risk factors. The term 'cured' should be used when discussing the survivors' status with them and in the larger society; vice versa, the term 'long-term survivor' should continue to be used in scientific research and related literature to alert professionals to sequelae which require care and attention.
- The care of the child with cancer should include full and honest information for parents and the child (in an age- and culturally- appropriate manner) regarding the diagnosis of the disease, its management and its curability. The communication of 'cure' for an individual child or adolescent and his/her family should occur in the context of an agreed-upon decision taken by the paediatric oncologist in charge, with all persons involved, taking the individual circumstances into consideration.
- Communication of risk is difficult and challenging. Information about risk should be delivered to survivors and families in language that is easily understood and in a positive light. Effective communication requires a high level of interpersonal skills. Survivors and families have the right to be fully informed in person and in writing about being cured, as well as about the remaining risks of late effects, recurrence of the primary disease or second malignancies where applicable. After completion of treatment for the original cancer, it is the responsibility of the paediatric cancer unit (PCU) to provide the survivor and parents with a summary of the characteristics of the disease, of treatments received, and of complications that may have occurred during therapy. The summary must be combined with suggestions on the type and timing of the follow-up evaluations to monitor the original cancer as well as possible late effects of the disease and its treatment. When the survivor enters adulthood, he/she should be referred to an appropriate health care provider who coordinates long term care. If any specific problem arises that might be considered a possible late effect of treatments received during childhood, the survivor should be referred to an appropriate specialist. The PCU should provide the specialist with as comprehensive a medical history of the former patient as possible. The PCU should be available to receive and retain records on the long-term status of former childhood cancer patients.
- There is an additional need for continuing systematic follow-up after cure for surveillance of possible long-term effects of the cancer or its treatment. To this end, every PCU should have a well-structured 'follow-up clinic' and a multidisciplinary team including one or more of the following: paediatric oncologist, nurse, psychologist, and social worker plus other relevant specialists based on individual patient needs.
- In order to provide appropriate and definitive advice and support to long term survivors, the PCU needs to collect further information through audit and research. In prioritising a research agenda, the health care professionals should collaborate with survivors and their families. Evidence-based counselling requires the collection of research data on which to base recommendations. Results of such research should be linked back to the provider community and to survivors and families, for incorporation into future practice.
- Systematic efforts should be made during and after cancer treatment to empower the survivors and families by making available age-appropriate information, and strengthening their coping skills and strategies in dealing with their current and future concerns. Most survivors and their families cope well. By reinforcing these adjustment skills and strengthening their coping strategies, they will develop a resilience that will help them to face and overcome, ever more forcefully and confidently, future life challenges. These strategies will be especially important in dealing with the formal transition from active treatment to after-treatment, from after-treatment to long-term care, and from the paediatric to the adult-focused health care system. A specific contact person should be designated to facilitate these transitions.

7. As stated, the majority of the survivors are relatively well adjusted; indeed there is a proportion with extraordinary resilience. However, compared to the general population, some survivors are at an increased risk of developing conditions that need medical, psychological or social care. The health care system must address all these groups.
8. Parents, siblings, and other close family members should always be encouraged to play an active role in the discussion of future plans, and in the design and implementation of psycho-social interventions. In addition, survivors and parents have a useful role to play in sharing information and life skills, helping to empower other survivors and parents, and in the design and implementation of future services. Parents and advocacy groups should be included as active members in the multidisciplinary health care team.
9. The general public needs to be made aware of and accept the reality of the cure of childhood cancer: that significant progress over the past 30 years in the treatment of childhood cancers has resulted in many hundreds of thousands of survivors who are cured and are now completing school, entering adulthood, and living full lives as active members of society. This population increases every year. The larger society should ensure that survivors have equal access to education, jobs, insurance, and medical care.
10. Inequalities of current treatment strategies and cure rates, both within and between nations, based largely on differences in socio-economic status and resource allocation, remain a challenge for the international community to address.

3. NOTE

It is not possible to provide an exact definition of cure that applies to all cancers. For the purpose of this document, in the context of childhood cancer survivorship, the group agreed on the use of the following concept of cure. Cure after cancer during childhood refers only to the original disease regardless of any potential for, or presence of, disabilities or side effects of treatment. Children who have been treated for cancer can be considered cured when they have reached a time point at which the chance that they will die from their original disease is no greater than that of age peers in the general population of dying from any cause.

For many of the malignant diseases of childhood a patient who survives free of relapse for a certain number of years after diagnosis according to the type of tumour, can be considered cured. The time to cure depends on tumour type, stage, and other biological factors. In general, it is between 2 and 10 years relapse-free since cancer diagnosis. For some other tumours, attempting precision is unreliable because of underlying strong genetic factors involved in the causation of and response to the specific cancer.

4. List of participants at the Erice workshop

Epidemiologists: Julianne Byrne (Chair, Ireland), Guido Pastore (Italy), Maria Grazia Valsecchi (Italy), Peter Kaatsch (Germany), Mike M. Hawkins (Birmingham)

Nurses: Faith Gibson (Chair, United Kingdom), Moira Bradwell (United Kingdom), Ulrika Kreicbergs (Sweden), Nelia Langeveld (The Netherlands), Anne Thorvildsen (Norway), Kathleen Ruccione (United States)

Parents: Mark Chesler (Chair, United States), Irina Ban (Serbia), Marianne Naafs-Wilstra (The Netherlands), Maria Pia Serrafiero Bonini (Italy), Christine Wandzura (Canada)

Physicians: Giuseppe Masera (Chair, Italy), Ronald D. Barr (Canada), Joern D. Beck (Germany), Jos Bokkerink (The Netherlands), Gabriele Calaminus (Germany), Andreas Feldges (Switzerland), Giulio J. D'Angio (United States), Riccardo Haupt (Italy), Momcilo Jankovic (Italy), Herwig Lackner (Austria), Thorsten Langer (Germany), Edina Magyary (Hungary), Renée Maurus (Belgium), Luisa Massimo (Italy), Concetta Micalizzi (Italy), Anja Moericke (Germany), Jacques Otten (Belgium), Pierre Philippet (Belgium), Gregory Reaman (United States), Cor van den Bos (The Netherlands), Anjo J. P. Veerman (The Netherlands)

Psychologists: John J. Spinetta (Chair, United States), Christine Eiser (United Kingdom), Cinzia Favara (Italy), Pilar Gonzalez-Doupe (United Kingdom), Gabriela Medin (Spain), Bob Last (The Netherlands), Pia Massaglia (Italy)

Survivors: Anthony Penn (Chair, United Kingdom), Eva Coenen (The Netherlands), Angelamaria Cometa (Italy), Marieke van de Wetering (The Netherlands)

Conflict of interest statement

None declared.

Acknowledgement

The Erice workshop was organised thanks to the support of the G. Gaslini Foundation, San Paolo Foundation, Buitoni s.p.a., and M. Letizia Verga Committee. We thank Ms. Carla Mangani for excellent secretarial and editorial assistance.