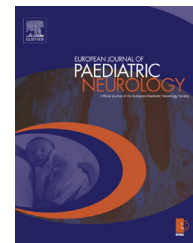




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Review article

Strategies to improve the quality of survival for childhood brain tumour survivors



Gesche Tallen ^{a,b,*}, Anika Resch ^c, Gabriele Calaminus ^d, Andreas Wiener ^d, Ulrike Leiss ^e, Thomas Pletschko ^e, Carsten Friedrich ^{c,f}, Thorsten Langer ^g, Desiree Grabow ^h, Pablo Hernáiz Driever ^a, Rolf-Dieter Kortmann ⁱ, Beate Timmermann ^j, Torsten Pietsch ^k, Monika Warmuth-Metz ^l, Brigitte Bison ^l, Ulrich-Wilhelm Thomale ^m, Jürgen Krauss ⁿ, Martin Mynarek ^c, Katja von Hoff ^c, Holger Ottensmeier ^o, Michael Frühwald ^p, Christof M. Kramm ^q, Petra Temming ^r, Hermann L. Müller ^s, Olaf Witt ^t, Uwe Kordes ^c, Gudrun Fleischhack ^r, Astrid Gnekow ^p, Stefan Rutkowski ^c, on behalf of the German Paediatric Brain Tumour Consortium (HIT-Network)

^a Department of Paediatric Oncology/Haematology, Charité-Universitätsmedizin Berlin, Campus Virchow, Augustenburger Platz 1, 13353 Berlin, Germany

^b Department of Paediatrics, Faculty of Medicine, University of Calgary, 2888 Shaganappi Trail N.W., Calgary, Alberta T3B 6A8, Canada

^c Department of Paediatric Haematology and Oncology, University Medical Centre Hamburg-Eppendorf (UKE), Martinistr. 52, 20246 Hamburg, Germany

^d Department of Paediatric Haematology and Oncology, University Hospital Münster, Albert-Schweitzer-Campus 1, 48149 Münster, Germany

^e Medical University Vienna, Department of Paediatric and Adolescent Medicine, Währinger Gürtel 18-20, 1090 Vienna, Austria

^f Division of Paediatric Oncology, Haematology and Haemostaseology, Department of Woman's and Children's Health, University Hospital Leipzig, Liebigstr. 20a, 04103 Leipzig, Germany

^g Department of Paediatric Oncology/Haematology, University of Lübeck, Ratzeburger Allee 160, 23538 Lübeck, Germany

^h German Childhood Cancer Registry (GCCR), Institute of Medical Biostatistics, Epidemiology, and Informatics (IMBEI), University Medical Center, University of Mainz, Gebäude 902, Obere Zahlbacher Straße 69, 55131 Mainz, Germany

* Corresponding author. Department of Paediatric Oncology/Haematology, Charité-Universitätsmedizin Berlin, Campus Virchow, Augustenburger Platz 1, 13353 Berlin, Germany. Tel.: +49 030 450 566032; fax: +49 030 450 566906, Department of Paediatrics, Faculty of Medicine, University of Calgary, 2888 Shaganappi Trail N.W., Calgary, Alberta T3B 6A8, Canada. Tel.: +1 403 955 7802; fax: +1 403 955 3065.

E-mail addresses: gesche.tallen@charite.de (G. Tallen), a.resch@uke.de (A. Resch), gabriele.calaminus@ukmuenster.de (G. Calaminus), andreas.wiener@ukmuenster.de (A. Wiener), ulrike.leiss@univie.ac.at (U. Leiss), thomas.pletschko@meduniwien.ac.at (T. Pletschko), carsten.friedrich@medizin.uni-leipzig.de (C. Friedrich), c.friedrich@uke.de (C. Friedrich), thorsten.langer@uksh.de (T. Langer), desiree.grabow@unimedizin-mainz.de (D. Grabow), pablo.hernaiz@charite.de (P.H. Driever), rolf-dieter.kortman@medizin.uni-leipzig.de (R.-D. Kortmann), beate.timmermann@uk-essen.de (B. Timmermann), Torsten.Pietsch@ukb.uni-bonn.de (T. Pietsch), warmuth_m@ukw.de (M. Warmuth-Metz), bison_b@ukw.de (B. Bison), uthomale@charite.de (U.-W. Thomale), krauss.j@ukw.de (J. Krauss), m.mynarek@uke.de (M. Mynarek), k.von-hoff@uke.de (K. von Hoff), ottensmeie_h@ukw.de (H. Ottensmeier), michael.fruehwald@klinikum-augsburg.de (M. Frühwald), christof.kramm@med.uni-goettingen.de (C.M. Kramm), petra.temming@uk-essen.de (P. Temming), mueller.hermann@klinikum-oldenburg.de (H.L. Müller), olaf.witt@med.uni-heidelberg.de (O. Witt), kordes@uke.de (U. Kordes), gudrun.fleischhack@uk-essen.de (G. Fleischhack), astrid.gnekow@klinikum-augsburg.de (A. Gnekow), s.rutkowski@uke.de (S. Rutkowski).

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ⁱ Department of Radiation Oncology, University of Leipzig, Stephanstr. 9a, 04103 Leipzig, Germany

^j Particle Therapy Clinic at West German Proton Therapy Centre Essen, University Hospital Essen, Hufelandstr. 55, 45147 Essen, Germany

^k Institute of Neuropathology, University of Bonn, Sigmund-Freud-Str. 25, 53105 Bonn, Germany

^l Dept. of Neuroradiology, University of Würzburg, Josef-Schneider-Str. 11, 97080 Würzburg, Germany

^m Department of Paediatric Neurosurgery, Charité-Universitätsmedizin Berlin, Campus Virchow, Augustenburger Platz 1, 13353 Berlin, Germany

ⁿ Department of Neurosurgery, Head Clinic, University of Würzburg, Josef-Schneider-Str. 11, 97080 Würzburg, Germany

^o University Children's Hospital Würzburg, Dept. of Paed. Haematology, Oncology, Josef-Schneider-Str. 2, 97080 Würzburg, Germany

^p Department of Paediatric Oncology/Haematology, Klinikum Augsburg, Stenglinstr. 2, 86156 Augsburg, Germany

^q Division of Paediatric Haematology and Oncology, University of Göttingen, Robert-Koch-Str. 40, 37075 Göttingen, Germany

^r Paediatric Haematology/Oncology, Paediatrics III, University of Essen, Hufelandstr. 55, 45147 Essen, Germany

^s Paediatric Oncology/Haematology, Klinikum Oldenburg, Medical Campus University Oldenburg, Rahel-Straus-Str. 10, 26133 Oldenburg, Germany

^t German Cancer Research Centre (DKFZ) and Department of Paediatric Oncology/Haematology, University of Heidelberg, Heidelberg, Im Neuenheimer Feld 280, 69120 Heidelberg, Germany

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ABSTRACT

Background: Tumours of the central nervous system (CNS) are the most frequent solid tumours and the second most frequent type of cancer in children and adolescents. Overall survival has continuously improved in Germany, since an increasing number of patients have been treated according to standardised, multicentre, multimodal treatment recommendations, trials of the German Paediatric Brain Tumour Consortium (HIT-Network) or the International Society of Paediatric Oncology-Europe (SIOP-E) during the last decades. Today, two out of three patients survive. At least 8000 long-term childhood brain tumour survivors (CBTS) are currently living in Germany. They face lifelong disease- and treatment-related late effects (LE) and associated socioeconomic problems more than many other childhood cancer survivors (CCS).

Method: We review the LE and resulting special needs of this particular group of CCS.

Results: Despite their increasing relevance for future treatment optimisation, neither the diversity of chronic and cumulative LE nor their pertinent risk factors and subsequent impact on quality of survival have yet been comprehensively addressed for CBTS treated according to HIT- or SIOP-E-protocols. Evidence-based information to empower survivors and stakeholders, as well as medical expertise to manage their individual health care, psychosocial and educational/vocational needs must still be generated and established.

Conclusion: The establishment of a long-term research- and care network in Germany shall contribute to a European platform, that aims at optimising CBTSs' transition into adulthood as resilient individuals with high quality of survival including optimal levels of activity, participation and acceptance by society.

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