

Title	Young adult patients with a pediatric disease in history: impact on course of life and transition into adulthood	Are survivors of childhood cancer with an unfavourable psychosocial developmental trajectory more likely to apply for disability benefits?	Measuring perceived benefit and disease-related burden in young cancer survivors: validation of the Benefit and Burden Scale for Children (BBSC) in the Netherlands	Sleep disorders in children after a brain tumour
Purpose	Course of life in young adults grown up with a chronic or life-threatening paediatric disease	Psychosocial developmental trajectory of survivors of childhood cancer with and without disability benefits	Validation of the Benefit and Burden Scale for Children (BBSC) in the Netherlands	Sleep disorders in children after a brain tumour, medical risk factors and associations with fatigue and psychosocial functioning
Sample characteristics	<p>Young adults grown up with chronic or life-threatening disease N=650: 348 survivors childhood cancer, 93 anorectal malformations, 72 Hirschsprung's disease, 61 oesophageal atresia, 76 end-stage renal disease Age at study: 18.0-30.9yrs. Age at diagnosis: 0.0-17.0 yrs 45.9-50.3% female, but 16.7% females in Hirschsprung's disease</p> <p>Reference group N=508: Dutch peers without a history of cancer 53.0% female Age at study: M=24.2 yrs (18.0-30.9)</p>	<p><i>Childhood cancer survivor (CCS)</i> with disability benefits N=53 without disability benefits N=313: Age at study: 17.7 – 31.1 yrs Age at diagnosis: 0.0-17.0 yrs Diagnosis: - with benefits 40.4% CNS cancer - without benefits 5.4% CNS cancer Gender: - with benefits 62.3% female - without benefits 48.6% female</p> <p><i>Reference group</i> N=508: Dutch peers without a history of cancer Age at study: M=24.2 yrs (18.0-30.9) 53.0% female</p>	<p>Paediatric survivors of childhood cancer N=77: 48% female Age at study: M=13.8 (8 – 18) yrs Age at diagnosis: M=10.2 (SD=3.6) yrs Time since diagnosis: M=3.2 (SD=1.4) End of treatment: M=1.8 (SD=0.9) yrs Mixed diagnosis: 64.9% leukaemia/lymphoma, 27.3% solid tumour, 7.8% CNS cancer</p>	<p>CNS N=31: 35.5% female Age at study: M=11.8 (5.3 – 17.7) yrs Age at diagnosis: M=9.0 (3.4 – 16.5) yrs End of treatment: M=1.9 (0.5 – 4.0) yrs</p> <p>non-CNS N=78: 47.4% female Age at study: M=9.7 (4.0 – 17.9) yrs Age at diagnosis: M=6.3 (0.0 – 16.9) yrs End of treatment: M=2.6 (0.5 – 6.0) yrs</p>
Measures	Course of life questionnaire (LVJV)	Course of life questionnaire (LVJV)	Benefit and Burden Scale for Children (BBSC) Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales, State Trait Anxiety Inventory for Children (STAI-C), Children's Revised Impact of Event Scale (CRIES), Strengths and Difficulties Questionnaire (SDQ)	Sleep Disorder Scale for Children (SDSC), Epworth Sleepiness Scale (ESS) Pediatric Quality of Life Inventory (PedsQL) Multidimensional Fatigue Scale, Strengths and Difficulties Questionnaire (SDQ)
Main results	<p>Young adults grown up with a chronic or life-threatening disease, as a total, achieved fewer psychosocial developmental milestones than the reference group in all five domains: autonomy development, social development, psychosexual development, substance use and gambling, antisocial behaviour.</p> <p>The course of life of young adults grown up with oesophageal atresia was not delayed compared with that of the reference group. The course of life of survivors of childhood cancer and patients with end-stage renal disease was delayed most.</p>	<p>Compared with the reference group, both CCS with and CCS without disability benefits had lower scales scores in the social and psychosexual domain.</p> <p>CCS with disability benefits had lower scale scores in the social and psychosexual domain than CCS without disability benefits.</p> <p>CCS with disability benefits scored less favourable than the reference group on 14 out of 22 psychosocial developmental milestones. CCS without disability benefits scored less favourable than the reference group on 6 out of 22 psychosocial developmental milestones.</p> <p>In conclusion, CCS with an unfavourable developmental trajectory while growing up were more likely to apply for disability benefits in adulthood than CCS with a more favourable development.</p>	<p>Internal consistency – Cronbach's alpha: Benefit 0.84, Burden 0.72. Test-retest reliability – Benefit r=0.74, Burden r=0.78 Homogeneity – mean inter-item correlation: Benefit r=0.34, Burden r=0.22</p> <p>Burden was associated with HRQoL (-), anxiety (+), posttraumatic stress symptoms (+), behavioural problems (+). Benefit did not correlate with the psychological outcomes.</p> <p>In conclusion, the Dutch version of the BBSC has promising psychometric properties.</p>	<p>Increased somnolence was found in CNS tumour patients compared to non-CNS. Both patient groups reported more problems than the norm with initiating and maintaining sleep.</p> <p>No specific medical risk factors were identified for a sleep disorder in CNS tumour patients.</p> <p>Excessive somnolence was correlated with lower fatigue-related HRQoL and worse psychosocial functioning.</p>
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