Activities of daily living and quality of life in survivors of childhood brain tumour

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Computer Graphic Designer: Paule Samson, 2015

INTRODUCTION

- Innovations in medical technology have led to earlier diagnoses and improved treatment of cancers, increasing the survival rate to nearly 70% for children with brain tumours (BT) in North America (American Cancer Society, 2009; Canadian Cancer Society, 2011). Nevertheless, survivors are left to struggle with a host of issues that often leave them unnecessarily disabled or only able to function at a level that is not optimal. The impact of late effects on function and daily living activities are poorly documented and quantified; existing research that measured performance in activities of daily living (ADL), from an objective perspective using standardized evaluation tools, are rare in the literature (Parks et al., 2009).

OBJECTIVES

- The aim of this research is to address the functional outcomes and health-related quality of life (HRQoL) of adolescent and young adult survivors of childhood BT. The focus is on performance in ADL and HRQoL as they reflect the everyday life of survivors beyond the acute diagnosis and treatment phases.
  - The **primary objective** is to estimate the extent to which survivors of childhood BT achieve a level of performance in ADL that is comparable to their peers 5 years after diagnosis.
  - The **secondary objectives** are:
    1) to explore the association between observed limitations in motor and process skills and the HRQoL;
    2) to determine which factors are likely to be associated with performance limitations.

METHODS

A cross-sectional study

Participants

- A convenience sample of 36 survivors of childhood BT recruited from a long-term follow-up clinic at CHU Ste-Justine in Montréal
- Inclusion criteria:
  - Age ≥16 years at the time of the study,
  - Brain tumour as the first cancer occurrence,
  - Being at least 3 years off treatment with no recurrence or progression and at least 5 years since diagnosis

Measures

- Assessment of Motor and Process Skills (AMPS): a standardized objective measure, was used to evaluate the quality of ADL task performance.
- SF- 12 questionnaire: a generic instrument, to measure HRQoL.
- Socio-demographic questionnaire to document their current occupation, level of education, and living situation.

Procedure

- Medical charts review to obtain clinical data
- Assessment session scheduled during a follow-up visit at CHU Ste-Justine or at a time and location of their convenience :
  - Participants completed the SF-12 questionnaire and the socio-demographic questionnaire
  - AMPS was administered by the main researcher (a calibrated AMPS rater). Participants were observed while performing two ADL tasks.



RESULTS

Characteristics	
Age at evaluation (16-29 years)	21.0 ± 3.3
Gender	22 female : 14 male
Level of education (highest diploma)	
Elementary school	13 (36.1)
High school	9 (25.0)
Cegep* or professional school	11 (13.9)
University	3 (8.4)
Occupation	
Studying or working full-time	20 (55.6)
Studying special program, sheltered employment or part-time	13 (36.1)
Unemployed	3 (8.3)
Independence status	
Independent	6 (16.7)
Living with family or in resource	30 (83.3)
Time since end of treatment (years)	10.1 ± 3.8
Age at diagnosis (years)	8.9 ± 5.1
Tumor type	
Medulloblastoma or PNET	23 (63.9)
Astrocytoma or glioma	5 (13.9)
Other	8 (22.2)
Tumor location	
Posterior fossa	19 (52.8)
Supratentorial or parasellar	17 (47.2)
Type of treatment	
No radiation	1 (2.8)
Cranial radiation	7 (19.4)
Cranial and spinal radiation	28 (77.8)
Radiation dose	
<55Gy	20 (55.6)
≥55Gy	16 (44.4)
Chronic health conditions	
Endocrine	30 (83.3)
Musculoskeletal	17 (47.2)
Neurologic or neurosensory	27 (75.0)
Rehabilitation Services	
Occupational therapy	24 (66.7)
Physiotherapy	27 (75.0)
Psychology or neuropsychology	24 (66.7)
Speech Therapy	4 (11.1)

Note: Mean± SD or N(%); *N* = 36
*pre-university/college in education system of the province of Québec, Canada

Table 1. Personal and clinical characteristics of the study participants

	Survivors	Norms	p
Motor skills (logits)			
Mean	1.77	2.95	<0.05
SD	0.77	0.53	
95% CI	1.52 – 2.02		
Process skills (logits)			
Mean	1.29	2.01	<0.05
SD	0.64	0.43	
95% CI	1.08 – 1.49		

Note: SD = standard deviation; *N* = 36

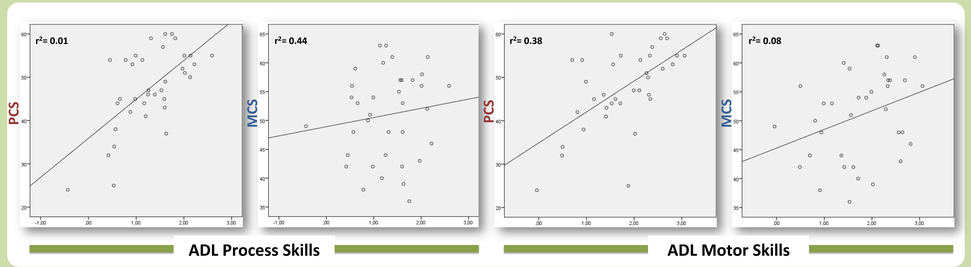
Table 2. Results of mean ADL Motor and ADL Process Abilities in comparison with age norms (one-sample t-test)

	Survivors	Norms	p
Mental Component Scale			
Mean	50.27	50	0.465
SD	7.55	10	
95% CI	37.89 – 63.01		
Physical Component Scale			
Mean	48.16	50	0.106
SD	9.33	10	
95% CI	45.11 – 51.21		

Note: SD = standard deviation; *N* = 36

Table 3. Results of SF-12 questionnaire in comparison with population norms (one-sample t-test)

Figure 1. Association between process skills, motor skills and scores on the Physical Component Scale (PCS) and Mental Component Scale (MCS) scales of the SF-12.



Characteristics	Motor skills		Process skills	
	OR	95% CI	OR	95% CI
Gender	5.143*	1.176-22.483	1.446	0.341-6.136
Age at diagnosis	3.545	0.765-16-433	7.6*	1.609-35.906
Time since treatment	0.2*	0.048-0.837	0.275	0.060-1.267
Tumor type	2.464	0.732-8.291	1.451	0.455-4.629
Tumor location	9.0*	1.972-41.075	1.747	0.437-6.972
Treatment type	0.388	0.077-1.963	1.080	0.212-5.949
Dose of radiation	0.372	0.094-1.472	1.467	0.367-5.858
Relapse	0.571	0.091-3.608	0.5	0.085-2.939
Chronic health conditions	0.057*	0.006-0.515	1.163	0.021-1.266

Note: OR = Odds ratio; CI = confidence interval; *significant p<0.05

Table 4. Association between motor and process skills and clinical characteristics (n=36)

DISCUSSION

- The performance in ADL was significantly lower compared to age-norms (p<0.05)
- The functional level was found to be positively associated with the physical component scale (r2=0.5) and the mental component scale (r2=0.3) of the SF-12
- Lower level of functioning was associated with age at diagnosis for process skills; and gender, tumour location, time since treatment and chronic health conditions for motor skills.

CONCLUSION

- Understanding the impact of cancer and its treatment on the life of childhood cancer survivors emphasizes the importance of the long-term follow-up. It also provides foundation for the creation of specialised rehabilitation programs aiming at improving the functional level and HRQoL of survivors.

ACKNOWLEDGEMENTS

- This research was supported by the Coast-to-Coast Foundation. We would like to acknowledge the contribution of the oncology rehabilitation team of the CHU Ste-Justine and to thank the participants for their very precious time and generosity.

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