



Profile of Daily Life in Children with Brain Tumors: An Assessment of PedsQL 4.0 Generic Core Scales before and after Treatment

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Abstract

BACKGROUND: Pediatric brain tumors are the most common solid tumor and cause of death among all childhood cancers. In America, brain tumor prevalence is 21.42/100.000 population. Even though survival rate is improving, the impact of treatment for long-term quality of life is still a challenge.

AIM: We aimed to investigate quality of life score using PedsQL 4.0 Generic Core Scales.

METHODS: The data collected based on the inclusion criteria from patient's medical records 2015–2017 period on January 2018–May 2018 in Siloam Hospital, Lippo Village, Karawaci. Twenty-six brain tumor pediatric patients with surgical treatment were evaluated using PedsQL 4.0 Generic Core Scales. The evaluation included before and after condition of the patient. PedsQL 4.0 Generic Core Scales were divided into four categories; physical function, emotional function, social function, and school function. They were analyzed statically using Wilcoxon test with $p < 0.05$ considered as statistically significant.

RESULTS: The result showed that before treatment score of PedsQL 4.0 Generic Core Scales was classified as medium functioning (58.54/92) and after treatment score of PedsQL 4.0 Generic Core Scales was classified as intermediate functioning (37.3/92).

CONCLUSION: The conclusion is that patient after treatment (surgery, chemotherapy, and radiation) shows improved quality of life score using PedsQL 4.0 Generic Core Scales.

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Introduction

Pediatric brain tumor is the most common solid tumor and cause of death among all childhood cancers. The prevalence of pediatric brain tumors at the United States are 21.42/100.000 population with incidence 1500–2000 children's every year. As a result of medical technology development, mortality has been reduced significantly but morbidity also increased [1], [2]. Brain tumor can affect quality of life including physic and psychology of pediatric in daily life activity. Besides that, brain tumor also can influence intellectual, emotional, and academic of pediatrics. Factors that can influence pediatric quality of life are complex including brain tumor itself, family socioeconomy, health-care provider, family education background, interpersonal factor, and culture. Several factors of brain tumor that can affect morbidity are location and extension of tumor, age, and increased intracranial pressure [3], [4].

Nowadays, quality of life measurement has important role in brain tumor treatment in pediatrics.

One of questionnaire that has been widely used is PedsQL 4.0 Generic Core Scales. PedsQL 4.0 Generic Core Scales can be used to measure physic, emotional, social, and academic function of pediatrics. This questionnaire can be filled by self-report or by parent proxy report. PedsQL 4.0 Generic Core Scales contain 8 questions for physic function, 5 questions for emotional emotion, 5 questions for social function, and 5 questions for academic function. Quality of life is also important part of brain tumor treatment in pediatric. As more pediatric brain tumor survive, the need of longterm follow up and monitoring of quality of life continue to need development [5], [6].

Methods

This research used observational cross-sectional design to study the quality of life of pediatric brain tumors survival in Siloam Hospital, Lippo Village,

Tangerang, Indonesia. All children between two and 18 years old with confirmed primary brain tumor that completed therapy and survived for at least 6 months were included in this study. From 2015 to 2017, there are 43 pediatrics screened but only 26 pediatrics participate the study. Excluded patients were 5 children discontinued treatment, 11 pediatrics were died, and 1 patient refused to participate. Patients quality of life was evaluated with PedsQL 4.0 Generic Core Scales. Questionnaires were answered by patients and their parent through phone calls while patients history from medical records.

Informed consent from all patients and their parents with ethical approval from Ethics Committee of Universitas Pelita Harapan was acquired before the study. Questionnaires will be asked directly to patients if above 9 years old and could communicate well, and aside from that answered from their parents. All 26 patients or their parents have to answered 23 questions PedsQL simultaneous before and after treatment with only three answers, i.e. no problem, sometimes, and big problem. All the collected data will be proceed into four categories, i.e. high functioning (0–24 point), intermediated functioning (26–46 point), medium functioning (48–68 point), and low functioning (70–92 point). This study was analyzed statistically using the SPSS® statistic version 24 (Armonk, NY). Paired t-test was used on normal distribution and Wilcoxon when not normal distributed with confidence interval of 95%.

Results

Characteristics of patients that followed this study are shown in Table 1. Mean age of this study is 14–18 years old (35%). This study was dominant in male (65%) but equal in brain tumor type.

Table 1: Patients’ characteristics

Variable	n	%
Age		
2–5 years old	4	15
6–9 years old	3	12
10–13 years old	6	23
14–18 years old	9	35
>18 years old	4	15
Sex		
Male	17	65
Female	9	35
Brain tumor type		
Benign	13	50
Malignant	13	50

From 26 patients that participated in this research, 14 questionnaires were answered autoanamnesis while others 12 questionnaires by their parents. PedsQL contains four categories physical (8 questions), emotional (5 questions), social (5 questions), and school function (5 questions). From physical function, before surgery, all questionnaires were answered quite poor (n = 16, 62%) and poor (n = 10, 38%) but after surgery became good (n = 6, 23%),

quite good (n = 7, 27%), quite poor (n = 13, 50%), and none answered poor. From emotional function, before surgery, result was good (n = 3, 11%), quite good (n = 16, 62%), quite poor (n = 5, 19%), and poor (n = 2, 8%) but after surgery, result became good (n = 10, 38%), quite good (n = 10, 38%), quite poor (n = 4, 16%), and poor (n = 2, 8%). From social function, before surgery, result was good (n = 0), quite good (n = 9, 35%), quite poor (n = 14, 54%), and poor (n = 3, 11%) but after surgery, result became good (n = 10, 38%), quite good (n = 12, 46%), quite poor (n = 2, 8%), and poor (n = 2, 8%). From school function, before surgery, result was good (n = 0), quite good (n = 14, 54%), quite poor (n = 8, 30%), and poor (n = 4, 16%) but after surgery, result became good (n = 9, 35%), quite good (n = 14, 54%), quite poor (n = 0), and poor (n = 3, 11%). From quality of life, before surgery was good (n = 0), quite good (n = 4, 16%), quite poor (n = 17, 65%), and poor (n = 5, 19%) but after surgery, result became good (n = 7, 27%), quite good (n = 13, 50%), quite poor (n = 6, 23%), and poor (n = 0) (Table 2).

Table 2: Results of PedsQL before and after surgery

Result	Before treatment (%)					After treatment (%)				
	a	b	c	d	e	a	b	c	d	e
Good	0 (0)	3 (11)	0 (0)	0 (0)	0 (0)	6 (23)	10 (38)	10 (38)	9 (35)	7 (27)
Quite good	0 (0)	16 (62)	9 (35)	14 (54)	4 (16)	7 (27)	10 (38)	12 (46)	14 (54)	13 (50)
Quite poor	16 (62)	5 (19)	14 (54)	8 (30)	17 (65)	13 (50)	4 (16)	2 (8)	0 (0)	6 (23)
Poor	10 (38)	2 (8)	3 (11)	4 (16)	5 (19)	0 (0)	2 (8)	2 (8)	3 (11)	0 (0)

a: Physical function, b: Emotional function, c: Social function, d: School function, e: Quality of life.

Comparison between before and after surgery result showed improvement in every category except emotional function. Result for quality of life before surgery is quite poor (58.54) and becomes quite good (37.3) after surgery. Result for physic function before surgery is quite poor (23.61) and becomes quite good (15.54) after surgery. Result for social function before surgery is quite poor (12.69) and becomes quite good (7.38) after surgery. Result for school function before surgery is quite poor (12.54) and becomes quite good (7.38) after surgery. Result for emotional function before surgery is quite good (9.69) and increases after surgery but still in quite good category (7.0) after surgery. All the results were analyzed using Npar test and Wilcoxon signed-rank test with p < 0.05. Analysis showed significant improvement in all categories (Table 3).

Discussion

All children with brain tumor with surgical treatment without chemotherapy and radiotherapy were included in research. This research showed that

Table 3: Analysis of PedsQL using Npar test, Wilcoxon signed-rank test

Treatment	Mean±SD	Min/max	p value
Quality of life			
Before	58.54 ± 11.57	38/84	0.000*
After	37.3 ± 14.24	16/66	
Physical function			
Before	23.61 ± 3.35	18/32	0.000*
After	15.54 ± 5.38	6/24	
Emotional function			
Before	9.69 ± 4.26	4/20	0.029*
After	7.0 ± 6.46	0/20	
Social function			
Before	12.69 ± 3.79	6/20	0.000*
After	7.38 ± 5.85	0/20	
School function			
Before	12.54 ± 3.73	8/20	0.000*
After	7.38 ± 5.11	2/20	

surgical treatment improves quality of life in all daily function significantly (Table 3). Improvement of from quite poor to quite good was found in all functions except in emotional function but still improved significantly. A study by Kim *et al.* showed that global quality of life and emotional function were significantly improved, but physical function was aggravated, especially for dyspnea, communication deficit, and leg weakness. Quality of life was mostly influenced by financial difficulty and future uncertainty [7]. A study by Kuhlthau *et al.* from 142 children (aged 2–18 years) with brain tumor and completed treatment protocol also showed similar result. Health-related quality of life from these children improves significantly after treatment at the 3 years follow-up. Physical health scores somewhat below psychosocial health score and within the score showed that the worst result was school functioning followed by emotional and social functioning scores [8].

Multicenter study from Canada using retrospective cohort study with 800 survivors of brain tumor below 18 years old compared to 923 control patients that were matched with age and gender was done to show children development outcomes and certain neurological deficit. This study showed that most common social problems to survival were learning disability and emotional problems and has no close friends especially survivors that have cranial radiation. Other deficits that found in brain tumor survivors were decrease in dexterity, hearing, speech, and cognition [9].

Another study by Macartney *et al.* to characterize the symptom experience and health-related quality of life from 50 children (aged 2–18) who have completed brain tumor therapy. This study showed that the most common symptoms encountered by the participants were lack of energy, pain, headache, disturbance of concentration, and sleep problem. These symptoms were independently related to decrease of quality of life [10]. Similar result was showed by Collins *et al.* study from 160 children (aged 10–18) with cancers. This study also resulted that the most common symptoms that related to quality of life is lack of energy, pain, nausea, loss of appetite, and psychological problems such as sadness, nervousness, worrying, and irritability [11].

Children with brain tumor that survived after surgery have to bear lifelong problem caused by neurological deficits due to tumor itself or treatment

complications. These children also had substantial neurocognitive problems with serious risk for endocrine problems. Several patients need long-term support systems, i.e., rehabilitation, psychosocial support, and regular medication, not a simple assignment even in good health-care systems. The problems faced by these patients not only about medical but more about social, familial, and health-care systems [12], [13].

This study used questionnaire by phone called so the limitation was not capable to evaluated children's expression. However, expression evaluation did not influence the final result of this research. The advantage of this study is the questionnaire that used can present the quality of life through four functions.

Conclusion

Quality of life in children with brain tumor before and after surgery showed significant improvement including physical, emotional, social, and school function. Surgical intervention was not only effective in managing brain tumor but also in improving quality of life.

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