

Assessment of health-related quality of life in children with cancer using PedsQL™ (a preliminary study)

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Abstract

Background Cancer in children can adversely affect their developments and growth. The assessment of health-related quality of life (HRQL) will justify its physical and psychological effects.

Methods Seventy-seven subjects who underwent therapy were assessed using the PedsQL™, which consisted of parent-proxy reports and or child-self reports. PedsQL™ is assessments of physical, social, emotional and role functions. The control group was students with the same number and age as the sample group.

Results Children with cancer had lower HRQL than normal healthy children (odds ratio 3.7). Children with cancer who came from low socio-economic families had lower social functions and girls had tendencies to have lower quality of life. Fathers' education had strong influence in children's quality of life. Leukemic patients had better quality of life than those of lymphoma and solid organ tumor. Group with age of diagnosis at 6-9 year old had lower HRQL compared with younger or older groups. The longer period of illness was, the more emotional function would improved. Despite of a good accordance between parents' and child's reports, parents usually had reports about having lower quality of life.

Conclusions Children's HRQL is influenced by clinical characteristics and social-demographic variables differently. Assessment of the children's HRQL is better done with parents and or child as the source of information. [Paediatr Indones. 2009;49:330-6].

Keywords: quality of life, cancer, children.

Malignancy or cancer in children is a common finding. The success of the cancer management is not solely measured by the physically healthy child, but also with the production of a good quality of life religiously and psycho-socially. Children who suffer from cancer can experience physical, mental, and social function disturbances as a result not only from the malignancy itself but also from the side effects of the treatment.¹⁻² Studies done in adults who suffered from cancer in their childhood then successfully healed, found differences in psycho-social and cognitive functions in comparison with the normal group.³⁻⁶

Good results are expected to achieve from advanced knowledge in the medical field nowadays such as increment number of cancer patients healed. However, special attention to the quality of life of the survivors needs to be highlighted. Survival-rate and health status are relatively easier to measure but unfortunately, these things fail to describe

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psychosocial effects of both cancer and its treatment.⁷ The measurement of health-related quality of life (HRQL) using instruments with validity and reliability standards has a role in determining the effects of a disease to the physical and psychosocial status which include emotional, social, and role-playing.⁸⁻¹⁰ The goal of the study was to measure the quality of life of children with malignancy in the Department of Child Health in Cipto Mangunkusumo Hospital and have it compared with quality of life of normal healthy children.

Methods

This was a cross sectional study measuring the HRQL of children with cancer and compared it with control group. The Pediatric Quality of Life Inventory (PedsQL) was a standardized modular instrument designed to measure HRQL in children and adolescent aged 2-18 years. The PedsQL consisted of 23 items divided between physical, social, emotional and role function, it was designed as child-self report and parent-proxy report. PedsQL was created by James W. Varni and had a high level of internal and external reliability, and it had been translated into many foreign languages.^{8-9,11-12} The Indonesian version of PedsQL was retrieved from MAPI Research Institute after completing the requested requirements. Seventy-seven consecutive oncology patients, who received chemotherapy on August until December 2008, at the Department of Child Health in Cipto Mangunkusumo Hospital (CMH), were approached to participate in this study. After completing the informed consents, children aged 5-18 years completed the PedsQL

child self-report, and the parents of children aged 2-18 year old completed the PedsQL proxy-reports. The parents also completed the social-demographic profile questions, while the clinical characteristics of the subjects were retrieved from their medical records. The PedsQL scores were computed based on the sum of the converted score divided by the number of items answered, with the range of score from 0-100. The higher score indicated higher HRQL.

Control group was students from two different elementary-junior high schools, which was chosen randomly with matching age and sex with the study group. Statistical analysis of the data was performed using the SPSS 15.0. The comparison of HRQL and the correlation of socio-demographic variables and clinical characteristics to HRQL were then retrieved.

Results

The study was able to retrieve 77 subjects with malignancy that fit the inclusion criteria with age ranging from 2.2 to 14.8 years old. Most subjects were in the range of 2-5 years old (34), 6-9 years of age was in 23 subjects; while 10-18 years of age was in 20 subjects. The mean age for the control group was 7.8 years old with the minimum age was 2.5 years old and maximum age was 14 years old.

A comparison of the HRQL scores between children with cancer and the healthy controls is shown in **Table 1**. The total score of HRQL in the study group was reported as significantly lower than the control group (mean total score: 64.29 vs. 80.73; $P < 0.001$; OR: 3.7). Physical, psychosocial, social, emotional and

Table 1. Comparison of HRQL of children with cancer and controls

	Total scores		Physical		Psychosocial		Emotion		Social		School	
	mean	P	mean	P	mean	P	mean	P	Mean rank	P	mean	P
Proxy report												
Case	64.29		62.87		65.37		58.56		41.86		53.07	
Control	80.73	<0.0001	84.48	<0.0001	78.65	<0.0001	70.17	0.003	66.99	<0.0001	73.11	<0.0001
OR	3.7	0.021	5.6	<0.0001	2.6	0.027	2.7	0.016			10.13	<0.0001
Parent report												
Case	62.03		6.29		62.95		55.92		61.77		50.16	
Control	73.97	<0.0001	63.24	0.018	76.13	<0.0001	62.96	0.003	93.23	<0.0001	67.10	<0.0001
OR	4.5	0.022	1.9	0.05	3.0	0.03	2.7	0.004			4.2	0.002

school functioning scores in the study group were also lower compared to those of the healthy control.

Table 2 compares the HRQL of children with cancer with different socio-demographic variables. Girls (n = 34) tend to have lower HRQL scores compared to boys (n = 43) in all functions measured but not significantly different (P = 0.36). This tendency was found in both parents' and children's

reports. Children with lower social-economic status (SES) have the tendency to have lower quality of life (QOL), especially in social function (n=65; mean rank: 24.39 vs. 35.35, P = 0.03). Parents' educational levels also influenced the child's QOL. Children whose parents had higher educational level, had tendencies to have higher QOL. Children whose fathers had low educational level (n=66), had lower

Table 2. Comparison of HRQL scores of children with cancer with different variables characteristics and duration of illness

	Total		Physical		Psychosocial		Emotion		Social		School	
	mean	P	mean	P	mean	P	mean	P	mean rank	P	mean	P
Sex												
Child Report												
Male	65.88	0.36	64.01	0.61	67.11	0.34	61.67	0.18	27.12	0.69	53.26	0.95
Female	61.51		60.88		62.37		53.18		25.42		52.18	
Parent Report												
Male	63.93	0.16	64.95	0.07	63.50	0.71	56.42	0.80	40.05	0.64	50.45	0.92
Female	59.64		56.66		62.25		55.30		37.68		49.82	
Social-Economic Status												
Child Report												
Low	62.36	0.84	61.27	0.27	63.32	0.07	56.42	0.15	24.39	0.03	49.88	0.09
High	72.38		69.59		74		67.5		35.35		63.33	
Parent Report												
Low	61.09	0.15	60.19	0.26	62.19	0.29	54.82	0.26	37.08	0.07	49.37	0.80
High	67.13		67.21		67.05		61.77		49.38		51.66	
Father's level of education												
Child Report												
Low	62.06	0.01	61.41	.17	62.76	<0.001	55.59	0.01	23.44	0.02	49.71	0.02
High	77.04		72.93		80.72		76.87		36.31		70.00	
Parent Report												
Low	61.30	0.72	60.90	0.28	62.07	0.08	54.64	0.06	36.69	0.15	49.11	0.38
High	69.27		68.40		71.11		67.77		47.61		59.28	
Mother's level of education												
Child Report												
Low	63.47	0.37	62.11	0.52	64.51	0.36	58.55	0.99	25.47	0.20	52.35	0.58
High	69.51		67.72		70.95		58.57		33.14		58	
Parent Report												
Low	61.75	0.23	60.88	0.26	62.73	0.40	52.61	0.56	37.21	0.10	48.93	0.48
High	68.08		69.64		67.61		56.14		51.21		59	
Duration of illness												
Child Report												
< 1 year	65.98	0.37	64.12	0.61	67.41	0.30	58.02	0.41	29.69	0.06	54.25	0.72
>1 year	61.78		61.01		62.36		60.08		21.79		51.75	
Parent Report												
< 1 year	62.67	0.56	60.76	0.76	64.28	0.26	55.18	0.65	40.64	0.36	53.76	0.75
>1 year	60.78		62.17		60.33		56.44		35.79		45.55	

QOL in total score, and psychosocial function. Group with longer duration of illness (n=34) had tendencies to have lower total score of HRQL, but a higher score was noted in emotional function. (child's report = 58.02 vs. 60.08, P= 0.41, parent's report= 55.18 vs. 56.44, P= 0.65).

The result of comparison of HRQL based on the primary diagnosis was summarized in **Table 3**. Using Post Hoc-test, leukemia groups (n= 46) were more likely to report better QOL in physical and psychosocial functions when compared with lymphoma (n=6) or solid tumors (n= 25) groups.

Based on the age of diagnosis (**Table 4**), subjects who were diagnosed at 6-9 year old (n= 20) had better

QOL compared with younger age group (2-5 year old, n= 43) and older age group (10-18 year old, n= 14). These superior results were found both in parents' and children's reports and in all measured-aspects.

Multivariate analysis of risk factors associated with poor QOL in the study group was shown in **Table 5**. Analysis was done on social-demographic and clinical variables. Both parents' and children's reports were analyzed, and based on the parents' reports there were no variable associated with poor QOL. On the other hand, based on the children's reports, poor QOL were associated with age of diagnosis and duration of illness. Group who were diagnosed at 2-5 year old were more likely to report poorer QOL when compared with

Table 3. Comparison of HRQL scores of children with cancer based on the primary diagnosis

QOL	Leukemia mean (n)	Lymphoma mean (n)	Solid Tumors mean(n)	P1	P2	P3
Children's reports						
Total	66.70 (36)	58.23 (6)	59.21 (10)	0.740	0.620	1.000
Physical	67.11 (36)	48.43 (6)	56.25 (10)	0.145	0.457	1.000
Psychosocial	66.51 (36)	65.27 (6)	61.33 (10)	1.000	1.000	1.000
Emotion	59.72 (36)	62.50 (6)	52.00 (10)	1.000	1.000	1.000
Social	28.90* (36)	22.42* (6)	20.30* (10)		0.212**	
School	50.83 (26)	66.67 (3)	55 (9)	0.699	1.000	1.000
Parents' reports						
Total	63.89 (46)	62.96 (6)	58.38 (25)	1.000	0.312	1.000
Physical	63.10 (46)	60.93 (6)	58.03 (25)	1.000	0.925	1.000
Psychosocial	64.65 (46)	64.93 (6)	59.33 (25)	1.000	0.437	1.000
Social	44.79*(46)	35.50*(6)	29.18* (25)		017**	
Emotion	56.95 (46)	59.37 (6)	53.20 (25)	1.000	1.000	1.000
School	46.66 (27)	66.67 (3)	54.24 (11)	0.367	0.862	1.000

Note: P1=P value for leukemia-lymphoma, P2 = P value for leukemia-solid tumors, P3 = P value for lymphoma – solid tumors. P value with Post Hoc test. * mean rank ** Kruskal-Wallis test

Table 4. Comparison of QOL scores of children with cancer based on the age of diagnosis

	2-5 years(n)	6-9 years (n)	10–18 years (n)	P1	P2	P3
Children Report						
Total	65.97 (18)	58.06 (20)	71.10 (14)	0.396	1.000	0.071
Physical	65.79 (18)	55.20 (20)	70.05 (14)	0.383	1.000	0.145
Psychologic	66.01 (18)	60.50 (20)	71.52 (14)	0.962	1.000	0.203
Social	23.89*(18)	25.27*(20)	31.61*(14)		0.313**	
Emotion	59.44 (18)	51.00 (20)	68.21 (14)	0.699	0.775	0.078
School	56.67 (12)	45.67 (15)	59.24 (14)	0.551	1.000	0.334
Parent Report						
Total	61.98 (43)	58.55 (20)	67.16 (14)	1.000	0.640	0.209
Physical	61.07 (43)	58.90 (20)	65.37 (14)	1.000	1.000	1.000
Psychologic	63.01(43)	59.33 (20)	67.92 (14)	1.000	0.827	0.281
Social	35.86* (43)	39.22*(20)	48.32*(14)		0.191**	
Emotion	55.61 (43)	52.00 (20)	62.50 (14)	1.000	0.762	0.378
School	54.11 (15)	44.00 (15)	53.18 (11)	0.518	1.000	0.758

Note: P1= P value for group 1 and 3, P2= P value for group 1 and 2, P3= P value for group 2 and 3. P= P value with Post Hoc test.* mean rank, ** Kruskal-Wallis test

Table 5. Multivariate analysis of risk factor associated with poor HRQOL (child report)

Variables	beta	P	OR	95% CI	
				Min	Max
Father's level of education	2.261	0.05	9.597	0.99	92.23
Aged of diagnosis	-1.003	0.009	0.367	0.172	0.779
2-5 years old	1.532	0.083	4.628	0.818	26.172
6-9 years old	-1.600	0.077	0.202	0.034	1.187
10-18 years old		0.001			
Duration of illness	-2.012	0.001	0.134	0.039	0.459

Table 6. Comparisons of the parents' reports and children's reports

Quality of life	Study group			Control		
	mean	SD	P	mean	SD	P
Total score						
Children's report	63.29	16.48	0.41	80.73	9.45	0.001
Parents' report	62.93	13.54		73.97	13.25	
Physical						
Children's report	62.87	21.58	0.66	84.49	11.85	<0.0001
Parents' report	61.29	19.27		63.24	21.93	
Psychosocial						
Children's report	65.37	17.17	0.39	78.65	10.19	0.203
Parents' report	62.95	14.59		76.13	11.99	
Emotion						
Children's report	58.55	22.21	0.47	62.96	16.8	0.714
Parents' report	55.92	19.53		70.17	17.64	
Social	Mean rank			Mean rank		
Children's report	71.31		0.11	76.47		0.017
Parents' report	60.74			60.86		
School						
Children's report	53.07	19.98	0.533	73.10	19.38	0.055
Parents' report	50.16	21.26		67.10	15.6	

those of who were diagnosed at 10-18 year old. Group who were diagnosed at 6-9 year old were less likely to report poorer QOL when compared with older group (OR: 0.2; 95%CI 0.03 to 1.18).

The problem that frequently arises with measurement of HRQL in children is determining the source of information. **Table 6** compares the results of parents' reports and children's report in study and control group. Parents reported lower scores compared with children, and these were found in both groups; therefore in general, there was good accordance between parents' and children's reports.

Discussion

This study provides information regarding HRQL in children between 2-18 year old with cancer, who underwent treatment using the PedsQL™. In

Indonesia, the measurement of HRQL in children with chronic illness, especially cancer, is not a routine procedure; despite of the benefits that can be drawn by retrieving the QOL of a child with a chronic illness. In this study, children with cancer reported to have lower QOL scores that were statistically significant compared to healthy controls. Many studies also reported the same results.^{8,13-14} Sex and its influence to QOL were often studied and the results were variable. In this study, girls tend to have lower QOL compared to boys, of which is similar to the study by Wu et al.¹³ On the other hand, studies done by Landolt et al¹⁴ and Kazak et al¹⁵ reported differently. This difference states that sex was not main factor associated with QOL. Lower SES was frequently associated with lower QOL as was found in this study and a significant difference was found in social function.¹⁶ Study done by Zebrack et al¹⁷ concluded that SES was significantly related to risk for reporting lower depression scores, while a study

by Landolt¹⁴ could not find the correlation of SES with poor QOL. Parents' educational level influences the children's QOL, and in this study it was found that the lower fathers' or mothers' educational level, the lower psychosocial function tend to be.

The type and stage of malignancy influence some of the things such as; treatment course, procedures to be done, complications, and all that influence the child's QOL.¹⁸ In this study, leukemia group had higher QOL compared to lymphoma and solid tumors group. However, studies by Landolt et al and Meeske et al found that patients with brain tumor reported more problems compared to leukemia patients.^{14,19} Different protocols in different institutions or countries may also influence the patients' QOL.

Based on the age at the time of diagnosis, children diagnosed at 10-18 year old had better QOL compared to younger groups, and this was similar to the findings by Wu.¹³ In 10-18 year old group, children understood better about the disease process and its effects, thus they had better preparation about their perceptions and problem-solving attitudes.²⁰ In this study, the duration of illness also affected the QOL. Better emotional function was seen in the group with longer period of disease. In time, patients and their parents may have better acceptance and solve the problems they were faced with. Longitudinal scoring of different QOL revealed changes in QOL as in improvements of physical and or social functions.^{14,21} The QOL scoring would be well-presentated if it was done periodically and longitudinally. This kind of QOL can determine the effects, problem that may arise, and success of the treatment.

Multivariate analysis found that variables which influence QOL were the duration of illness and age at diagnosis. Study by Wu et al¹³ found that ethnicity influenced QOL, and no other risk factors could be identified. Different results from different studies showed a lot of variables could influence the QOL.

Parents' reports and children's reports have good accordance although parents usually reported to have lower QOL compared to children, this fact was also found in other studies.^{8,22-23} Parents' concern of their children will affect QOL. Anxious and depressed parents tend to score lower QOL despite the true nature of the child. The good accordance between the parents' and the children's reports showed that children can be used as reliable

source of information if the right tools were used, in accordance with the children's age and development. In determining a child's QOL, it is better to have both parent and child as the source of information to be able to gather information thoroughly. In conclusion, children's HRQL is influenced by clinical characteristics and social-demographic variables differently. Assessment of the children's HRQL is better done with parents and or child as the source of information.

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