

## Quality of life in children with cancer and their normal siblings

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### Abstract

**Background** Cancer treatment in children influences the quality of life of patients and their families. The Pediatric Quality of Life (PedsQL) inventory is a questionnaire to assess quality of life of the healthy and ill children.

**Objective** To compare quality of life in children with cancer and their normal siblings, and to compare quality of life in those with hematologic malignancies to those with solid tumors.

**Methods** A cross-sectional study was conducted among 5-to-18-year-olds at the Hematology-Oncology Division at Haji Adam Malik Hospital, Medan, North Sumatera, from May to July 2012. The case group (subjects with cancer) filled the PedsQL 3.0 and 4.0 questionnaires, while the control group (normal siblings) filled only the PedsQL 4.0 questionnaire. Independent T-test was used to compare the quality of life between children with cancer and their normal siblings.

**Results** There were 46 children in each group. The PedsQL 4.0 results in children with cancer and their normal siblings, and PedsQL 3.0 between hematology malignant and solid cancer were as follows: physical function 36.9 vs. 80.7, respectively (95%CI of differences -52.639 to -34.990; P= 0.0001), emotional function 40.4 vs. 69.3, respectively (95%CI of differences -35.912 to -21.914; P=0.0001), social function 71.5 vs. 93.9, respectively (95%CI of differences - 29.238 to -15.587; P=0.0001), school function 20.7 vs. 74.2, respectively (95%CI of differences - 62.124 to -44.832; P=0.0001), and total score 42.1 vs. 79.3, respectively (95%CI of differences - 43.066 to -31.344; P=0.0001). School function was the most affected parameter in children with cancer compared to their normal siblings.

**Conclusion** There is a significant difference in quality of life between children with cancer and their normal siblings, for all four parameters examined by the PedsQL inventory. However, there are no significant differences in quality of life between children with hematologic malignancy and those with solid cancer. [Paediatr Indones. 2015;55:243-7].

**Keywords:** child cancer, quality of life, Peds-QL

Globally, cancer is a leading disease in children, with the highest incidence at age 2-3 years. The incidence decreases by the age of 9 years, followed by another increase in adolescents.<sup>1</sup> Data from 2005-2007 hospital based cancer registry in DKI Jakarta Province (the Jakarta Special Capital Region) indicated that the cancer types in children aged 0-19 years were leukemia (11.6%), brain tumour (7.02%), osteosarcoma (4.41%), nasopharyngeal carcinoma (3.5%), lymphoma (2.83%), retinoblastoma (2.8%), soft tissue and solid tumour (2.4%), hepatoma (1.81%), wilms tumour/renal (1.58%), and testis (1.25%). Cancer on children is more common in males than in females.<sup>2</sup>

Cancer and its management not only affects the physical aspect of a child's quality of life, but also the social and emotional aspects. Approximately 75% of the average life expectancy of children with cancer is 5 years. General management such as chemotherapy,

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radiotherapy, and surgery, either palliative or curative, can cause adverse side effects as well as benefits, both for the children, their families, and health workers.<sup>3,4</sup> Assessment of quality of life in children with cancer is a concept that used to approach the health conditions of children with cancer diseases.<sup>1</sup> Past approaches to assess quality of life in children with cancer took only the physical health condition into account,<sup>1</sup> but quality of life is also affected by experiences, beliefs, expectations, and health perceptions.<sup>5</sup>

Children with cancer and their families often feel sadness, disappointment, despair, stress, depression, and anxiety. As such, assessment of the quality of life of children with cancer and their family members is needed to determine actions that improve their quality of life.<sup>6</sup> We aimed to compare the quality of life between children with cancer and their normal siblings, as well as quality of life between children with hematologic malignancies and those with solid tumors.

## Methods

A cross-sectional study was conducted in May to July 2012 in the Division of Hematology-Oncology, Haji Adam Malik Hospital, Medan, North Sumatera. Included were children aged 5 to 18 years with any type of cancer, who were undergoing chemotherapy at the time, and whose parents provided informed consent. Children filled the questionnaires (PedsQL 3.0 cancer module and PedsQL 4.0 generic core scales). We excluded children with mental retardation, remission, or severe malnutrition. The control groups were the normal siblings of the case group. The control group filled only the PedsQL 4.0 inventory. The PedsQL is a multidimensional instrument that is reliable and valid in healthy populations and in children with cancer. The Mapi Research Institute, France, provided the PedsQL 4.0 generic core scales, PedsQL 3.0 cancer module, as well as training for administering the scales.

Baseline characteristics were obtained from parents interviews and questionnaires. Subjects were divided into two groups, the case (46 children with cancer) and control (46 normal siblings) groups. Children with cancer consisted of they who had hematologic malignancies and those with solid tumors.

We used SPSS version 15.0 and Microsoft Excel 2007 for data processing. Independent T-test was used to compare quality of life between children with cancer and their normal siblings, as well as quality of life between children with hematologic malignancies and those with solid tumors. Differences were considered to be significant for P values <0.05 with 95%CI. This study received approval from the Research Ethics Committee of the University of North Sumatera Faculty of Medicine.

## Results

From the 62 children with cancer and their 62 normal siblings, 32 children were excluded due to not meeting the inclusion criteria. **Table 1** shows the characteristics of subjects. The mean age of both groups was 9.9 years, with males more common than females (58.7% vs. 41.3%). Hematological cancer was the most commonly found type of cancer (69.6%).

The demographic data of the cancer subjects is shown in **Table 2**. The most common type of cancer was leukemia (69.6%). Thirty-two subjects had hematological cancer and 30/32 had routine chemotherapy. Six subjects failed to complete routine chemotherapy due to lack of financial resources and/or

**Table 1.** Demographic data of subjects

Characteristics	Case group (n=46)	Control group (n=46)
Mean age (SD), years	9.9 (3.58)	9.9 (3.58)
Gender, n (%)		
Male	27 (58.7)	27 (58.7)
Female	19 (41.3)	19 (41.3)
Mean body weight (SD), kg	29.1 (11.30)	28.1 (8.15)
Mean height (SD), cm	132.1 (16.02)	131.1 (14.25)
Nutritional status, n(%)		
Underweight	40 (86.9)	44 (95.7)
Normoweight	3 (6.5)	2 (4.3)
Overweight	3 (6.5)	-
Level of education, n(%)		
Dropped out	-	2 (4.3)
Kindergarten	5 (10.8)	3 (6.5)
Primary school	31 (67.4)	29 (63.8)
Junior high	8 (17.4)	8 (17.3)
Senior high	2 (4.3)	5 (10.8)
Type of cancer, n(%)		
Hematological cancer	32 (69.6)	-
Solid cancer	14 (30.4)	-

**Table 2.** Characteristics of subjects with cancer

Characteristics	Hematological malignancy (n=32)	Solid tumor (n=14)
Initial cancer diagnosis, n		
<5 years ago	5	-
≥ 5 years ago	27	14
Cancer type, n		
Leukemia	32	-
Retinoblastoma	-	3
Nasopharynx carcinoma	-	3
Non-Hodgkin lymphoma	-	2
Osteosarcoma	-	2
Hodgkin Lymphoma	-	1
Germ cell tumor	-	1
Wilms tumor	-	1
Fibrosarcoma	-	1
Initial time of chemotherapy, n		
<5 years	5	-
≥ 5 years	27	14
Routine chemotherapy, n		
Yes	30	10
No	2	4
Symptoms during chemotherapy, n		
No	-	2
Sometimes	10	5
Always	22	7
Chemotherapy phase, n		
Induction phase	18	8
Maintenance phase	13	5
Consolidation phase	1	-
Radiotherapy	-	1

P=0.0001), social function 71.5 vs. 93.9, respectively (95%CI of differences -29.23 to -15.58; P=0.0001), school function 20.7 vs. 74.2 (95% CI of differences -62.12 to -44.83; P=0.0001) with a total of 42.1 vs. 79.3, respectively (95%CI of differences -43.06 to -31.34; P=0.0001). The school function domain showed the lowest mean value in the case group.

**Table 4** shows the quality of life comparison between patients with hematologic malignancies and those with solid tumors. The eight-domain appraisal with the PedsQL 3.0 yielded the following scores: pain 34.3 vs. 32.1, respectively (95%CI of differences -29.28 to 29.28), nausea 27.8 vs. 19.6, respectively (95%CI of differences -26.97; 19:11), procedural anxiety 16.6 vs. 22.6, respectively (95% CI of differences -14.35 to 19.29), treatment anxiety 89 vs. 95.2, respectively (95%CI of differences -10.69 to 5.94), worry 77.3 vs. 73.2, respectively (95%CI of differences -26.93 to 18.36), cognitive problems 20.5 vs. 27.5, respectively (95%CI of differences -37.81 to 1.38), perceived physical appearance 66.4 vs. 54.7, respectively (95%CI of differences -26.10 to 41.57), and communication 54.2 vs. 65.4, respectively (95%CI of differences -48.11 to 18.35). There were no significant differences between groups for any of the domains.

**Table 3.** Comparison of quality of life between children with cancer and their normal siblings based on the PedsQL 4.0 inventory scores

Quality of life domains	Case (n=46)	Control (n=46)	95%CI of differences	P value
Mean score (SD)				
Physical	36.9 (28.49)	80.47 (11.41)	-52.63 to -34.99	0.0001
Emotional	40.4 (22.05)	69.3 (15.47)	-53.91 to -21.91	0.0001
Social	71.5 (20.26)	93.9 (11.01)	-29.23 to -15.58	0.0001
School	20.7 (19.0)	74.2 (21.24)	-62.12 to -44.83	0.0001
Overall total	42.1 (17.54)	79.3 (9.11)	-43.06 to -31.34	0.0001

administrative problems. Patients with hematological malignancies were almost always symptomatic during chemotherapy (22/32) compared to those with solid tumors (7/14). Cancer patients were most commonly in the induction phase.

**Table 3** shows the scores of the four domains assessed by the PedsQL 4.0 inventory in the case and control groups: physical function 36.9 vs. 80.7, respectively (95% CI of differences -52.63 to -34.99; P=0.0001), emotional function 40.4 vs. 69.3, respectively (95%CI of differences -35.91 to -21.91;

## Discussion

We compared quality of life of children with cancer to their healthy siblings. The majority of our cancer subjects had leukemia. Quality of life in children with cancer was significantly lower than in their normal siblings.

Cancer is the leading cause of nonaccidental death in childhood. Approximately 175,000 children worldwide are diagnosed with cancer.<sup>7</sup> Unless otherwise stated, the data on incidence are taken

**Table 4.** Comparison of quality of life between children with hematological malignancy and solid tumors

Quality of life domains	Hematological malignancy (n=32)	Solid tumors (n=14)	95%CI of differences	P value
Mean score (SD)				
Pain and hurt	34.3 (34.05)	32.1 (31.28)	-29.28 to 29.28	1.0
Nausea	27.8 (23.89)	19.6 (25.98)	-26.97 to 19.11	0.719
Procedural anxiety	16.6 (22.18)	22.6 (21.03)	-14.35 to 19.29	0.766
Treatment anxiety	89.0 (23.70)	95.2 (13.76)	-10.69 to 5.94	0.548
Worry	77.3 (29.07)	73.2 (30.53)	-26.93 to 18.36	0.689
Cognitive problems	20.5 (23.14)	27.5 (23.90)	-37.81 to 1.38	0.666
Perceived physical appearance	66.4 (31.78)	54.7 (43.08)	-26.10 to 41.57	0.630
Communication	54.2 (42.96)	65.4 (31.8)	-48.11 to 18.35	0.351
Overall total	48.1 (12.54)	47.3 (9.57)	-14.48 to 8.78	0.605

from the *International Incidence of Childhood Cancer* (IARC) study. The total incidence rate is usually in the range 70–160 per million children. There are marked variations between populations in the incidence of particular types of childhood cancer and these can provide valuable pointers to etiology. This international variation is largely accounted for by leukemia, which comprises around 80% of pediatric cancers in many populations.<sup>8</sup>

In pediatric cancer patients, the illness and treatment effects influence the quality of life of these children and their families. Therefore, it is important to assess the quality of life in both the patient and the family. The PedsQL instrument has been recommended and validated for use to assess quality of life for children with cancer and healthy children.<sup>9</sup>

A study in Pakistan showed a significantly lower quality of life in children with cancer compared to their healthy siblings.<sup>10</sup> Using the PedsQL 4.0, we found that physical, emotional, social and school functions were all significantly lower in children with cancer than in the healthy sibling control group. Undergoing treatment for cancer during childhood may cause physical, social, school and emotional concerns, thus impacting health-related quality of life.<sup>11,12</sup> An Italian study showed that children who underwent radiation treatment and children diagnosed under the age of 6 years have the greatest risk for difficulties in school function and are candidates for greater attention and preventive efforts.<sup>13</sup>

Limitations in physical performance is one of the potential long-term consequences following diagnosis

and treatment of childhood cancer. Disability implies a substantial decrease or absence of function. For these analyses, questions assessing activity limitations were used, such as mobility skills including lifting, carrying, climbing stairs, and walking one block, as well as functional status, a combination of participation skills including self-care, community mobility, and the ability to attend work or school.<sup>14</sup> An American study showed a 2.7-fold increased risk of activity limitations and a 5.2-fold increased risk of functional status impairment, relative to a sibling control group. Among the *Childhood Cancer Survivor Study* (CCSS) survivors treated between 1970 and 1986, those who survived brain tumors, bone tumors, or Hodgkin's disease appeared to be at greatest risk for physical performance limitations.<sup>15</sup> Another study showed performance limitations in 14.1% of survivors diagnosed with rhabdomyosarcoma as children, a group whose solid tumor type would suggest the potential for adverse physical performance outcomes, as well as 7% of leukemia survivors.<sup>16</sup>

In a comparison of subjects with hematologic cancer to those with solid tumors, the PedsQL 3.0 module cancer assessment revealed no significant differences in quality of life between the two types of malignancies. However, procedural anxiety was the domain most affecting the quality of life in both cancer groups. Pain due to cancer, side effects of chemotherapy, as well as pain or fear due to procedures, can affect the quality of life of children with cancer.<sup>17</sup> A British study showed, that children with cancer who underwent chemotherapy for one year on a regular basis had lower quality of life than

those without routine cancer chemotherapy, due to nausea, procedural anxiety and worry affecting the quality of life domains.<sup>18</sup>

A meta-analysis of studies on health-related quality of life in childhood cancer survivors in the European community found that pain was a lasting problem in about one-third of patients.<sup>19</sup> Our study had limitations in sample size, little variation in types of cancer in our subjects, and the majority in both cancer groups were undergoing chemotherapy in the induction phase.

We conclude that there is a significant difference in quality of life between children with cancer and their normal siblings, for all four parameters examined by the PedsQL inventory. However, there are no significant differences in quality of life between children with hematologic malignancy and those with solid cancer.

### Conflict of interest

None declared.

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