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 hematologic 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. 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 tumor (7.02%), osteosarcoma (4.41%), nasopharing carcinoma (3.5%), lymphoma (2.83%), retinoblastoma (2.8%), soft tissue and solid tumor (2.4%), hepatoma (1.81%), Wilms tumor/renal (1.58%), and testis (1.25%). Cancer on children is more common in males than in females.

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.\textsuperscript{3,4} Assessment of quality of life in children with cancer is a concept that used to approach the health conditions of children with cancer diseases.\textsuperscript{1} Past approaches to assess quality of life in children with cancer took only the physical health condition into account,\textsuperscript{1} but quality of life is also affected by experiences, beliefs, expectations, and health perceptions.\textsuperscript{5}

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.\textsuperscript{6} 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. \textbf{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 \textbf{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

| 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 | Solid tumor |
|--------------------------|--------------------------|-------------|
|                          | (n=32)                   | (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           |

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  |

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. Unless otherwise stated, the data on incidence are taken...
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.8

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.9

A study in Pakistan showed a significantly lower quality of life in children with cancer compared to their healthy siblings.10 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.11,12 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.13

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.14 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.15 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.16

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.17 A British study showed, that children with cancer who underwent chemotherapy for one year on a regular basis had lower quality of life than

### 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 |
|------------------------|-------------------------------|-------------------|----------------------|--------|
| 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  |
those without routine cancer chemotherapy, due to nausea, procedural anxiety and worry affecting the quality of life domains.\textsuperscript{18}

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.\textsuperscript{19} 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.

References

1. Smith MA, Ries LA. Childhood cancer: incidence, survival, and mortality. In: Pizzo P, Poplack D, editors. Principles and practice of pediatric oncology. 3rd ed. Philadelphia: Lippincott Raven; 2005. p. 1481-93.
2. Bagian Penelitian dan Pengembangan, Rumah Sakit Kanker Dharmais, Pusat Kanker Nasional. Laporan Kerja Subbagian Registrasi Kanker: Registrasi kanker berbasis rumah sakit di RSKD tahun 2012. Jakarta: Balitbang RSKD; 2012. p. 62-5.
3. Lanckowsky P. Evaluation, investigation, and management of late effects of childhood cancer. In: Lanckowsky P, editor. Manual of pediatric hematology and oncology. 4th ed. San Diego: Elsevier Press; 2005. p. 749-73.
4. Blauwbroek R, Groenier KH, Kamps WA, Meyboom-de Jong B, Postma A. Late effects in adult survivors of childhood cancer: the need for life-long follow-up. Ann Oncol. 2007;18:1898-1902.
5. Halyard MY, Ferrans CE. Quality-of-life assessment for routine oncology clinical practice. J Support Oncol. 2008;6:221-9.
6. Pechal A, Graf A, Bergstraesser E, Landolt MA. A two-session psychological intervention for siblings of pediatric cancer patients: a randomized controlled trial. Child Adolesc Psychiatry Ment Health. 2012;6:1-9.
7. Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Sales-Schatz S, et al. Symptoms and suffering at the end of life in children with cancer. N Engl J Med. 2000;342:126-33.
8. Stillier CA. Epidemiology and genetics of childhood cancer. Oncogene. 2004;23:6429-44.
9. Varni JW, Burwinkle TM, Katz EB, Meeske K, Dickinson P. The PedsQL\textsuperscript{TM} in pediatric cancer: reliability and validity of the Pediatric Quality of Life Inventory Generic Core Scales, Multidimensional Fatigue Scale, and Cancer Module. Cancer. 2002;94:2090-106.
10. Chaudry Z, Siddiqui S. Health related quality of life assessment in Pakistani paediatric cancer patients using PedsQL\textsuperscript{TM} 4.0 generic core scale and PedsQL\textsuperscript{TM} cancer module. Health Qual Life Outcomes. 2012;10:52-66.
11. Ness KK, Hudson MM, Ginsberg JP, Nagarajan R, Kaste SC, Marina N, et al. Physical performance limitations in the Childhood Cancer Survivor Study cohort. J Clin Oncol. 2009;27:2382-9.
12. Spieth LE, Harris CV. Assessment of health-related quality of life in children and adolescents: an integrative review. J Pediatr Psychol. 1996;21:175-93.
13. Adamoli L, Deasy-Spinetta P, Corbetta A, Jankovic M, Lia R, Locati A, et al. School functioning for the child with leukemia in continuous first remission: screening high-risk children. Pediatr Hematol Oncol. 1997;14:121-31.
14. World Health Organization. Towards a common language for functioning disability and health: ICF The International Classification of Functioning, Disability and Health; 2002. [cited 2012 November]. Available from: http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf.
15. Hudson MM, Mertens AC, Yasui Y, Hobbie W, Chen H, Gurney JG, et al. Health status of adult long-term survivors of childhood cancer: a report from the Childhood Cancer Survivor Study. JAMA. 2003;290:1583-92.
16. Punyko JA, Gurney JG, Scott Baker K, Hayashi RJ, Hudson MM, Lia Y, et al. Physical impairment and social adaptation in adult survivors of childhood and adolescent rhabdomyosarcoma: a report from the Childhood Cancer Survivors Study. Psychooncology. 2007;16:26-37.
17. Schor N, Lottick K, Worth L, Bleyer A, Tubergen D, Bradby B, et al. Cancer and benign tumors. In: Kliegman RM, Behrman RE, Jenson HB, Stanton BF, editors. Nelson pediatrics. 18th ed. Philadelphia: Sanders Company; 2008. p. 2091-162.
18. Landolt MA, Vollrath M, Niggli FK, Gnehm HE, Sennhauser FH. Health-related quality of life in children with newly diagnosed cancer: a one year follow-up study. Health Qual Life Outcomes. 2006;4:63-70.
19. Calaminus G, Kiebert G. Studies on health-related quality of life in childhood cancer in the European setting: an overview. Int J Cancer Suppl. 1999;12:83-6.