

and correlations between parent and clinician re-

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Assessment of QOL during Treatment of Children with Acute Lymphoblastic Leukemia—Part 2

Yasushi Ishida, Etsuko Nakagami-Yamaguchi, Teruaki Hongo, Hiroki Hori, Urara Koudera, Hiroaki Hisakawa, Miyako Toshinari-Ouchi, Kikuko Kuriyama, Shuichi Okada, Hideaki Ohta, Keiko Yumura-Yagi, Keizo Horibe, Junichi Hara and on behalf of QOL Committee of the Japan Association of Childhood Leukemia Study (JACLS)
St. Luke's International Hospital, Department of Pediatrics

We conducted a prospective cohort survey from a patient's viewpoint using self-rating questionnaires on quality of life (QOL) of the children (10 years of age or older) with acute lymphoblastic leukemia (ALL) who were treated with the Japan Association of Childhood Leukemia Study (JACLS) protocol from April 1997 to March 2008. Five domains including physical well-being, daily activities, emotional well-being, relationship to medical stuffs, and family well-being were evaluated each 4 times during treatment. We obtained informed consent of their guardians and solicited anonymous responses to a questionnaire by mail. We received the questionnaires back from 401 patients but excluded 19 sheets because of missing basic data of the patients.

We compared QOL scores of ALL-97 (n = 215) with those of ALL-02 (n = 167). The total scores and subtotal scores of daily activity, emotional well-being and family relationship domains were higher in ALL-02 than in ALL-97. In each patient the change of mean total scores showed various patterns during any treatment phases with a small improvement. The more patients answered in ALL-02 group than ALL-97 group that the examination and therapy were not big burden on them and that the relationship to medical stuff was good. There is good correlation in total scores and subtotal scores of physical well-being domain but poor correlation in emotional well-being, family relationship and relationship with medical stuff domains between the patient-rating and their parent-rating.

This study suggested that QOL can be measured by the self-rating questionnaires and a clinical research on childhood QOL should be conducted multi-dimensionally including the patients' points of view if possible.

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事務局：独立行政法人国立病院機構

名古屋医療センター臨床研究センター内

〒460-0001 名古屋市中区三の丸4丁目1番1号

TEL:052-951-1111 FAX:052-963-5503

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