

# Health Related Quality of Life of Children with Chronic Illness

Vini S Kumar<sup>1</sup>, Baby S Nayak<sup>2</sup>, Yashoda S<sup>3</sup>

## Abstract

*A descriptive survey was carried out with the aim of determining the health related quality of life (HRQOL) of hospitalised children with chronic illness. Data was collected from 148 children with chronic illness admitted in selected paediatric wards of tertiary care hospitals and their parents. The results showed that 51 percent of the children scored below the median of total HRQOL score. Children with cancer 34 (91.9%) and thalassemia 33 (89.2%) reported a low HRQOL. Children with chronic illness especially cancer and thalassemia had significantly low HRQOL compared to children with other illnesses. Gender, diagnosis, frequency of hospitalisation, duration of illness and type of treatment received were the predictive of HRQOL of these children.*

The success and failure of any medical system depends on mortality and morbidity rates. The current trends in medical system focus on third dimensions of health care that is quality of life. Health-related quality of life (HRQoL) is defined by the World Health Organisation (1993), as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns”. Illnesses are classified as either acute or chronic. Chronic illness is as an illness that recurs or persists for a long period of time and may last for a person’s entire life.

## Review of Literature

A study conducted in Spain to examine the impact of disease and hospitalisation on 105 children aged 6-15 years showed that daily living activities and psychological well-being were impaired. The study also reported close relationship between emotional states and perceived quality of life (González-Gil, et al 2008).

Another study conducted in Switzerland to assess the HRQOL in children during the first year after diagnosis of cancer and an examination of demographic, medical, and parental predictors of HRQOL reported more of physical complaints, reduced motor functioning and autonomy, and impaired positive emotional functioning 6 weeks after

diagnosis. HRQOL significantly improved over the year. Children with leukemia were more affected at six weeks whereas children with brain tumour complaints more of physical symptoms at one year than other group. (Landolt, et al 2006).

A study conducted in Thailand to assess the HRQOL of children with thalassemia aged 5-18 years revealed a positive relationship between age and HRQOL ( $b=0.243$ ,  $p<0.001$ ). Similarly, a significant relationship was also found between severity and HRQOL ( $b=-0.162$ ,  $p=0.003$ ) (Thavorncharoensap, et al 2010)

Limited literature is available in India focusing on HRQOL of hospitalised children. Multi-dimensional effects of the illness on children and families will be understood with the measurement of HRQOL for children who have chronic illness, so that planning, applying and evaluating the results of nursing care will guide in the better therapeutic outcome in the children. Understanding the areas affected in case of children with chronic illness is essential for delivering the care properly.

## Objectives

The study aimed at (a) Assessing the health-related quality of life (HRQOL) of children with chronic illness; and (b) Finding the association between HRQOL of children with demographic and disease variables.

## Methodology

The study adopted Survey approach with descriptive design. Data was collected from purposive sample of 148 children with chronic illness admit-

*The authors are:1. Department of Child Health Nursing, Manipal College of Nursing Manipal, Manipal University, Manipal; 2. Professor and HOD, Department of Child health nursing, Manipal College of Nursing Manipal, Manipal University; 3. Assistant professor, Department of Child health nursing, Manipal College of Nursing Manipal.*

ted in selected paediatric wards of tertiary care hospitals and their parents. The chronic illnesses included in the study were children with cancer, nephrotic syndrome, thalassemia and epilepsy. Critically ill children and children with cognitive impairment were excluded from the study.

The instruments used for the study were background information proforma and quality of life questionnaire (The Netherlands Organization for Applied Scientific Research Academical Medical Centre Child Quality of Life). Background information proforma consisted of three parts: demographic proforma, disease variable proforma and Kuppaswami Socioeconomic status scale. The validity and reliability of the tools were established. Permission to use the TACQOL was obtained from the author. The validity and reliability was of HRQOL was established and it was found to be valid and reliable to apply in Indian context. Pilot study was conducted among 20 children.

**Data collection:** The study was conducted in paediatric wards of tertiary care teaching hospital under Manipal University. Ethical clearance was obtained from the institution. Informed consent was taken from the parents after ensuring confidentiality. Afterwards, data related to HRQOL was collected from the children using TACQL questionnaire through interview. Data related to the background information proforma was collected from medical records and from parents.

## Results

Statistical analyses were performed using SPSS statistical package (version 11.5).

**Sample characteristics:** A total of 148 children participated in the study, 57 (38.5%) children were from the age group of 6-8 years. With respect to gender, 90 (60.8%) were males. With reference to socio-economic status 106 (71.6%) were from lower middle class family.

**Distribution of sample based on disease variable:** Equal number of children, 37 (25%) were taken from all the four category of diseases. In most, 70 (47.3%) of them the frequency of hospitalisation was once in a month. Duration of illness was between 6 months to 2 years in most (78, 52.7%) of them. Most, 73 (49.3%) of the children were receiving only medications as treatment

**HRQOL scores:** The total HRQOL was described in terms of the median and the domains were described in terms of mean and standard deviation. The median of the total HRQOL score was 78. The mean SD of the total HRQOL score was 78.75

(9.55). Among the domains, motor domain 11.05 (2.25), autonomy 11.47 (2.12) and bodily functions 11.54 (2.64) scored the lowest as shown in Table 1.

Association between the HRQOL and selected variables is presented in Table 2, which shows that a statistically significant association has been found between gender ( $\chi^2_{(df=1)} = 4.604$ ,  $p=0.042$ ), diagnosis ( $\chi^2_{(df=3)} = 79.44$ ,  $p=0.001$ ), frequency of hospitalisation ( $\chi^2_{(df=3)} = 57.38$ ,  $p=0.001$ ), duration of illness ( $\chi^2_{(df=1)} = 5.56$ ,  $p=0.02$ ) and type of treatment ( $\chi^2_{(df=3)} = 86.98$ ,  $p=0.001$ ) with HRQOL of children.

Among the sample, 61.1 percent of males and children with cancer (91.9%) and thalassemia (89.2%) reported a low HRQOL.

## Discussion

The finding of the present study showed a statistically significant association between type of treatment and HRQOL was congruent with that of Thavorncharoensap et al (2010) among children with thalassemia, who found that children receiving blood transfusion reported a low HRQOL. The association found between gender and HRQOL was contradicted by this study. The present study finding of association between HRQOL with duration of illness ( $p=0.02$ ) and type of treatment ( $p=0.001$ ) was contradicted by Miller & Tonya (2011) to compare the HRQOL of children with epilepsy with that of healthy controls, who found that duration of illness and type of treatment were not predictive of diminished HRQOL.

## Conclusion

The study concludes that children with chronic illness especially cancer and thalassemia will have a significantly low HRQOL. The domains affected also will vary widely based on the type of chronic illness. The HRQOL of children with chronic illness is influenced by factors like gender, diagnosis, frequency of hospitalisation, duration of illness and type of treatment received can be predictive of HRQOL. Thus interventions to promote

**Table 1: Mean and standard deviation of total HQOL score and scores of HRQOL domains**

| Areas             | Mean  | Standard deviation |
|-------------------|-------|--------------------|
| Total HRQOL score | 78.75 | 9.55               |
| Bodily functions  | 11.54 | 2.64               |
| Motor             | 11.05 | 2.25               |
| Autonomy          | 11.47 | 2.12               |
| Cognitive         | 12.64 | 1.86               |
| Social            | 13.03 | 1.28               |
| Emotion           | 19.03 | 3.55               |

**Table 2: Association between HRQOL of children with chronic illness and selected variables**

| Variables                           | Quality of life |                | $\chi^2_{(df)}$      | p value |
|-------------------------------------|-----------------|----------------|----------------------|---------|
|                                     | ≥ Median F (%)  | < Median F (%) |                      |         |
| <b>Gender</b>                       |                 |                |                      |         |
| Male                                | 35 (38.9)       | 55 (61.1)      | 4.604 <sub>(1)</sub> | 0.042*  |
| Female                              | 33 (56.9)       | 25 (43.1)      |                      |         |
| <b>Diagnosis of the child</b>       |                 |                |                      |         |
| Cancer                              | 3 (8.10)        | 34 (91.9)      | 79.44 <sub>(3)</sub> | 0.001*  |
| Nephrotic syndrome                  | 31 (83.8)       | 6 (16.2)       |                      |         |
| Thalassemia                         | 04 (10.8)       | 33 (89.2)      |                      |         |
| Epilepsy                            | 30 (81.1)       | 07 (18.9)      |                      |         |
| <b>Frequency of hospitalisation</b> |                 |                |                      |         |
| Once in a month                     | 12 (17.1)       | 58 (82.9)      | 57.38 <sub>(3)</sub> | 0.001** |
| Once in every 2 month               | 24 (58.5)       | 17 (41.5)      |                      |         |
| Once in every 4 months              | 25 (83.3)       | 05 (16.7)      |                      |         |
| Once in a year                      | 7 (100.0)       | 0              |                      |         |
| <b>Duration of hospitalisation</b>  |                 |                |                      |         |
| <1 week                             | 47 (50.5)       | 46 (49.5)      | 5.99 <sub>(3)</sub>  | 0.137** |
| 1-2 weeks                           | 20 (38.5)       | 32 (61.5)      |                      |         |
| 3-4 weeks                           | 0               | 2 (100)        |                      |         |
| >4 weeks                            | 1 (100)         | 0              |                      |         |
| <b>Duration of illness</b>          |                 |                |                      |         |
| 6 months – 2 year                   | 43 (55.1)       | 35 (44.9)      | 5.56 <sub>(1)</sub>  | 0.02*   |
| >2 years                            | 25 (35.7)       | 45 (64.3)      |                      |         |
| <b>Type of treatment</b>            |                 |                |                      |         |
| Only Medication                     | 60 (82.2)       | 13 (17.8)      | 86.98 <sub>(3)</sub> | 0.001*  |
| Radiation                           | 1 (50.0)        | 1 (50.0)       |                      |         |
| Blood transfusion                   | 4 (10.5)        | 34 (89.5)      |                      |         |
| Chemotherapy                        | 3 (08.6)        | 32 (91.4)      |                      |         |
| <b>History of other disease</b>     |                 |                |                      |         |
| Yes                                 | 01 (20.0)       | 4 (80.0)       | 1.52 <sub>(1)</sub>  | 0.37    |
| No                                  | 67 (46.95)      | 76 (53.1)      |                      |         |

\*significant at 0.05 level \*\*likelihood ratio

the QOL of hospitalised children should be the given importance in addition to routine care of the child.

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