

Evaluation of Health-related QOL in ill Adolescents through Subject's Self Report and Parent's Proxy Report.

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Abstract: Health-Related Quality of Life (HRQoL) is one of the most crucial outcome indicator in ill hospitalized adolescents as the Quality of Care (QoC) provided by hospitals greatly impacts their HRQoL. Moreover, to prevent physical and psycho-social impact of illness, it is important to determine how far the illness and its treatment compromise HRQoL. This cross-sectional study was conducted from 2009-2012 on ill adolescents availing in-patient care and their parents from the Department of Paediatrics, King George's Medical University, Lucknow. Previously validated WHOQOL-BREF was used for HRQoL assessment from parent's as well as subject's perspective. Baseline variables were summarized and reported. Spearman's correlations were computed between subject's self report and parent's proxy report of subject's HRQoL. Student's t-test was performed for bi-variate comparisons between parent's proxy HRQoL scores of ill subjects and the previously reported scores by parents of healthy subjects to understand the score variation in healthy versus ill sample. 300 ill adolescents were included (mean age 12.5 years \pm SD 2.6) out of which 184 (61.3%) were males. Correlations between subject's self report and parent's proxy report of subject's HRQoL were poor ($r=0.1-0.2$) with majority of the correlations being insignificant. This indicates poor associations between subject's self and parent's proxy report. Ill subjects had significantly lower scores than healthy adolescents in all HRQoL dimensions as well as global scores. **Conclusion-** The results of the study show that both illness and its treatment impact the HRQoL of adolescents. Hence, in addition to the clinical indicators that help in understanding the progress in treatment, the impact on HRQoL must also be studied through regular monitoring. Moreover, as the correlation between parent's proxy report and subject's self-report was very poor, preferably subject's self report must be obtained wherever possible.

INTRODUCTION

World Health Organization (WHO) defines Health-Related Quality of Life (HRQoL) 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, standards and concerns¹. HRQoL has recently been accepted as the most important outcome indicator for ill adolescents availing health care services² as Quality of Care (QoC) provided by hospitals to ill adolescents largely determines the HRQoL of ill adolescents availing care from the hospital³.

Hospital care, whether ambulatory or in-patient care, is considered as an interruption to normal life and may adversely affect psychosocial development as well as several other aspects of an adolescent's life⁴. HRQoL research in ill adolescents is utilized to identify those areas of an adolescent's functioning that are directly affected by an illness and the challenge of HRQoL research remains to identify these areas of functioning⁵. Conceptually, HRQL instruments are designed to assess a broader range of children's day-to-day functioning, that are not just limited to clinical measures, and thus if used in ill adolescents can provide unique information beyond clinical symptoms⁶. HRQoL thus refers to the subjective assessment of dysfunction associated with an illness or injury not only limited to physical aspect but also encompassing the non-observable psychosocial domains like pain, ability to fulfill personal and family responsibilities and overall life satisfaction⁵.

Studies illustrate that physicians who routinely received HRQoL data had significantly higher detection rates for psychological problems and functional HRQoL impairments in their patients. HRQoL measures can be utilized as standardized screening measures for

identifying physical and psychosocial health problems from both perspectives i.e. child and parent. Physicians may also benefit from 'serial screening approach' which utilizes longitudinal monitoring and thus can be useful in tracking changes in HRQoL over time and identify at-risk children in need of proactive care³. Moreover, to prevent physical and psycho-social problems due to illness, it is important to determine how far treatment and disease compromise the child's HRQoL across different dimensions⁷.

MATERIAL AND METHODS

This was a cross-sectional study conducted from 2008 to 2010 on ill adolescents availing in-patient care and their parents from the Department of Paediatrics, C. S. M. Medical University, Lucknow. Pyramid instrument was tested for reliability⁸ and utilized for QoC assessment from parent's perspective. Previously validated WHOQOL-BREF⁹ was used for HRQoL assessment from parent's as well as subject's perspective. Inclusion criteria was age of patient between 10-19 years, normal mental status to provide oral assent, availability of patient's parents, written informed consent from parents, and ability of parents to read or understand either Hindi or English. Patients were excluded if they did not fulfil the inclusion criteria and if the total length of stay of in-patients was less than 3 days. Pyramid instrument was interviewer-administered to parents to assess their perception of Quality of Care. WHOQOL-BREF was also interviewer-administered to subjects as well as their parents to obtain subject's self-report and parent's proxy-report of child's HRQoL. Self-administration method was avoided to ensure uniformity of mode of administration in the sample.

Data was computerized in a customized database and score calculation of WHOQOL-BREF and Pyramid was done as per their standard procedures^{10,11}. Overall mean HRQoL was computed for both instruments by averaging their respective domain scores. Data analysis was done using SPSS ver. 11.5 (SPSS, Inc., Chicago, IL,

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USA) and results with p-value d'' 0.05 were considered statistically significant.

RESULTS

300 patients were included out of which 184 (61.3%) were males and the mean age was 12.5 years (\pm SD 2.6). Mean gross monthly income (in INR) of study sample was Rs. 3,742 (\pm SD 2048), median income Rs. 3,500 with minimum and maximum income equal to Rs. 1000 and Rs.30,000, respectively. Mean missed school days of children was 11 days (\pm SD 8); 85 (28.3%) adolescents had missed school for less than 6 days, 131 (43.6%) had missed school for 6-10 days whereas 84 children (28%) had missed school for more than 10 days.

HRQoL scores as reported by subjects through self-report and the proxy report of subject's HRQoL as reported by parents was compared for associations. Cohen's k (Kappa) for agreement between item-scores of self and proxy reports was insignificant and could not be computed for several items due to unsymmetrical 2-way tables where values of both axes did not match to provide kappa results. Thus, correlations were computed for associations between domain scores reported through self and proxy reports of HRQoL are presented in table 1.

Table 1: Associations between domain scores reported through self and proxy reports of HRQoL

	Physical	Psychological	Social relations	Environment	Global QoL	Global health	Global HRQoL
Physical	0.09 ^{NS}	0.18 [†]	0.14*	0.2 [‡]	0.08 ^{NS}	0.08 ^{NS}	0.12*
Psychological		0.18 [†]	0.19 [†]	0.2 [‡]	0.1 ^{NS}	0.04 ^{NS}	0.9 ^{NS}
Social relations			0.21 [‡]	0.1 ^{NS}	0.03 ^{NS}	0.06 ^{NS}	0.6 ^{NS}
Environment				0.25 [‡]	0.05 ^{NS}	0.07 ^{NS}	0.08 ^{NS}
Global QoL					-0.006 ^{NS}	0.03 ^{NS}	-0.003 ^{NS}
Global Health						0.1 ^{NS}	0.09 ^{NS}
Global HRQoL							0.05 ^{NS}

* p-value <0.05, † p-value <0.01, ‡ p-value < 0.001, ^{NS} Not significant

As is clear from table 1, majority of the correlations were not significant, indicating poor associations between subject's self and parent's proxy report. Inter-dimension correlations between physical, psychological, social relations and environment dimensions were significant. Considering the global scores, only global HRQoL showed significant associations with physical dimension.

Results of student's t-test for bi-variate comparisons of parent's proxy HRQoL scores of the present ill sample and the scores of healthy subjects studied previously⁹ is shown in table 2.

Table 2: Comparison of Mean Parent's Proxy Hrqol Scores: Healthy Vs. Ill Subjects

HRQoL scores	Healthy subjects (n=525)* Mean \pm SD	Ill subjects (n=300) Mean \pm SD
Physical domain	73.6 \pm 14.04	42.57 \pm 7.4
Psychological domain	73.4 \pm 13.9	44.37 \pm 7.6
Social Relation domain	78.3 \pm 16.5	42.3 \pm 11.5
Environment domain	69.2 \pm 15.4	37.2 \pm 7.1
Global QoL	4.1 \pm 0.7	2.7 \pm 0.4
Global Health	3.9 \pm 0.8	2.5 \pm 0.5
Global HRQoL	3.9 \pm 0.6	2.6 \pm 0.36

All p-values<0.0001, * [9]

Results show that ill subjects had significantly lower scores in all HRQoL dimensions as well as global scores. The same is presented graphically in figures 1 and 2.

WHOQOL-BREF was thus found to have high discriminant validity for comparison across ill and healthy samples. Thus, it is a suitable

instrument for analyzing and comparing HRQoL among ill as well as healthy populations.

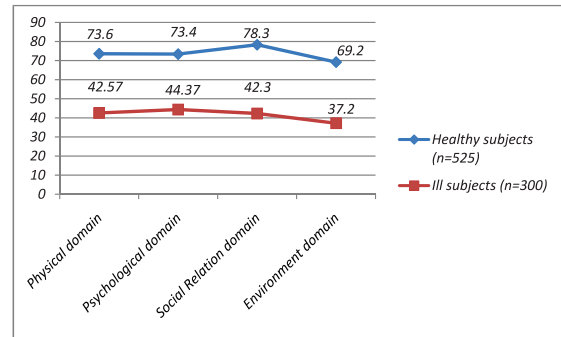


Figure 1: Comparative HRQoL domain scores of healthy and ill subjects

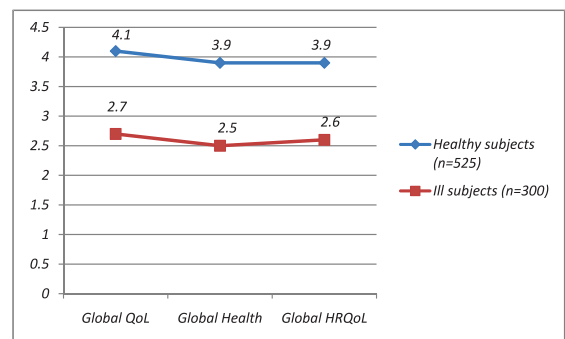


Figure 2: Comparative global scores of healthy and ill subjects

DISCUSSION AND CONCLUSION

In this study, we also utilized parental perspective because ill adolescents are dependent on their parents for healthcare services and thus, interaction occurs mainly between the health-care providers and parents^{12,13}. Therefore, parents have a uniquely appropriate perspective, which makes them most capable of evaluating various aspects of care provided to their child. Although the issue of parental participation and involvement in pediatric care is of growing importance the current literature on pediatric care is lacking in practical information on how to implement parents' views and experiences regarding parental involvement into clinical practice¹³.

Parents of hospitalized adolescents face 'double dilemma' as they are very keen to participate in their child's care at a level of their own choice but in majority of cases are unsure of their role for participation and thus suffer from 'parental role ambiguity' and lack of information¹³. Parents need information about child's illness in an understandable way to enable them for better participation in care¹².

However, this may not always be possible because of several barriers like language barriers, low health literacy, poor educational status¹³; parent's hesitation as staff seems to be very busy; parent's fear that questioning may appear to be criticism; parent's apparently weaker position due to unfamiliar hospital environment or just because hospital staff considers involving parents as unnecessarily time consuming process¹². In order to reduce these barriers and enhance parent's perception of QoC by improving their involvement in care processes, QoC assessment should be made a part of the health culture which will require teaching and training for patients as well as clinicians, nurses and other health workers¹⁴. It is observed that even when such assessments are initiated they get defeated in the long run due to limited resources and manpower.