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Assessment of Quality of Life in Iranian Asthmatic Children, Young Adults and Their Caregivers

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ABSTRACT

Interest in the impact of illness on day to day function is leading investigators to include both disease specific and generic health related quality of life (HR QOL) questionnaires in a broad range of clinical studies and to gain a full picture of the impact of asthma on the lives of children with this condition, it is necessary to make direct measurement of health related quality of life.

In response to this need, we used the Juniper's pediatric asthma quality of life questionnaire (PAQLQ) and Juniper's Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) that has been developed based on guidelines for construction of over a dozen validated disease specific quality of life instruments.

The PAQLQ consists of 23 items that in children with asthma have been identified as troublesome in their daily lives and PACQLQ that contains 13 items in two domains of emotional and activities disturbances. The study design consisted of an 18 month single cohort study. Patients participating in the study were 113 children, 7-17 years of age, with a wide range of asthma severity and their caregivers. For each patient a PAQLQ and for each caregiver a PACQLQ was completed. One week before visit patients recorded morning peak flow rates, medication use and symptoms in a diary. After complete physical examination, for determining of asthma severity, spirometry was performed.

The questionnaires after statically analysis showed good levels of both longitudinal and cross sectional correlations with the conventional asthma indices and with general quality of life. We found that consistently QOL in boys were more disturbed than females, a good relevancy between severity of asthma and QOL scores and more disturbances of QOL in caregivers of male asthmatic patients than caregivers of female asthmatic patients. We could not find any significant relevancy between FEV1 percentage of predicted and overall scores of QOL. Smaller airways, and higher airway resistance and more activity of males than females may explain why boys have more disturbed life style than females.

Key words: Asthma; Child; Iran; Quality of Life

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INTRODUCTION

Within the last few decades the concept of "good health" has moved from the "absence of disease or

illness” to a more positive concept which embraces the subjective experience of well being and quality of life.¹ In pediatrics, as in other areas of health care, awareness is growing that medical parameters such as mortality and morbidity are not the only important outcome variables to be considered when we evaluate child health interventions.¹⁻³ A quality of life perspective can identify sensitive child and adolescent issues that may be affected by illness or disability of treatment.^{4,5}

Definition of Quality of life: The term QOL, health and functional status are not interchangeable, nor are the instruments used to assess them.⁶⁻⁹

WHO definition of health: “A state of complete physical, mental, social well being, not merely absence of disease or infirmity.”¹⁰

WHO definition of QO L (1993): Individual perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.^{11,12}

Assessment of QOL can help the physicians in better understanding the results of their treatment not only in dimension of physical well being but also in spirit of treatment or QOL. This is for the first time that QOL has been assessed in our country. Comparison of our results with other nations and ethnics can be precious because we can find:

1) the effects of asthma standard therapy (GINA'S GUIDELINES) on different ethnics and genders.

2) the difference in emotional fragility due to the asthma between sexes according to their ethnicity

Another important factor is impact of asthma as a chronic disease on day to day functions of their caregivers. Any negative reflections as a vicious cycle will have non compensatory effects on the course of the disease in the patients, thus in this study we also assessed the QOL in the main caregivers of asthmatic patients.

PATIENTS AND METHODS

The study performed after approval from the ethics committee and Immunology, Asthma and Allergy Research Institute of Tehran University of Medical Sciences. A Persian version of Juniper's PACQLQ was prepared by both forward and backward translation by bilinguals after which a feasibility test was performed. Consecutive patients (n= 20) and their main caregivers (n=20) admitted to our clinic for measurement of QOL

with retest one month after discharge in the follow up clinic. Principle components analysis, intra class correlation, reliability, internal consistency and test retest reliability were assessed. Trivial rates of missing data confirmed the acceptability of the tools. Principal component analysis revealed that the domains and items in two questionnaires were performed as well as in the original studies. Study design consisted of an 18 month cohort study. We recruited 113 asthmatic subjects (57 males, 56 females), 7-17 years of age with a wide range of asthma severity and 113 primary caregivers of patients (mean age: 34.0 y). One week before visit, patients recorded morning peak flow rates, medication used and symptoms in a diary. After complete physical examination, for determining of asthma severity, spirometry was performed. Then according to GINA guide lines patient's asthma severity were step wised. For each patient a Juniper's PAQLQ and for each caregiver a Juniper's PACQLQ was completed. *PAQLQ*: contains: 23 items in three domains (Activity limitation= 5), Symptoms (n= 10), and emotional function= 8) *PACQLQ*: contains 13 items in two domains: Emotional function (n= 9) and Activity limitation (n= 4). Patients were excluded for the following reasons:

If they had any clinically significant abnormality or disease (other than asthma), if they had an acute upper or lower respiratory tract infection within 4 weeks before the start of trial or during the run-in period; or if they were taking other medication

Static Analysis

Asthma QOL was expressed as the mean score per item for each of domains of PAQLQ and PACQLQ. The overall score was derived from the mean score of all items. For each of domains and the overall score mean changes were analyzed .for statistical analysis a program SPSS 8.0 for WINDOWS surrounding has been used.

RESULTS

QOL in Male Patients

There was a good relevancy between severity of asthma and impairment of QOL in male patients - more severity of asthma, more impairment of each domain of activities, emotions and symptoms (p<0.05) (Table1). In this analysis we found that activities in males are more disturbed than the other domains.

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Table 1. Comparison of quality of life scores in asthmatic patients.

Asthma severity	Step I	Step II	Step III	Step IV	P-value
Total score (male patients)	5.3	4.2	3.4		<0.05
Total score (female patients)	6.7	4.7	3.5	2.3	<0.05
Activity(males)	5.76	4.11	3.23		<0.001
Activity(females)	6.8	4.4	3.7	2.2	<0.001
Emotion(males)	6.3	4.7	3.7		<0.001
Emotion(females)	6.9	5.07	3.8	2.37	<0.001
Symptoms(males)	6.1	4.61	3.3		<0.001
Symptoms(females)	6.75	4.38	3.57	2.1	<0.001

QOL in Female Patients

There was a good relevancy between severity of asthma and impairment of QOL in female patients- more severity of asthma, more impairment of each domains of activities, Emotions and Symptoms.

In this analysis we found that symptoms (coughs, tiredness, asthma attacks, wheezing, chest tightness) are more disturbed than the other domains. ($p<0.05$) (Table 1).

Comparison of Male and Female Asthmatic Patients QOL

According to severity of their asthma, QOL was more persistently impaired in male patients than females. There was not any male patient at step IV for comparison. ($p<0.05$) (Table 1).

Comparison of Domain of Activities

Male patients were more disturbed than female patients in each severity of asthma. ($p= 0.001$) (Table 1).

In comparison of domain of symptoms: male patients are more disturbed than females in each severity of asthma except in the case step II ($p<0.001$) (Table 1).

Comparison of Domain of Emotion

Male patients were more disturbed than females in each severity ($p<0.001$) (Table 1).

QOL in Caregivers

There was a good relevancy between severity of asthma, males and females and total score of QOL in their caregivers ($p<0.001$) (Table 2).

We found that QOL is more disturbed in caregivers of male patients than female patients. ($p<0.001$) table 2

Domain of activity e.g. interference with job, plans and sleepless nights, night awakening were more disturbed in caregivers of female patients than caregivers of male patients ($p<0.001$) (Table 2).

Domain of emotion e.g. feeling of frightening, helpless, frustration, upset, and angry were more disturbed in caregivers of male patients than caregivers of female patients. ($p<0.001$) (Table 2).

In caregivers of male patients domain of activity was more disturbed than domain of emotion ($p<0.001$) table 2. The same results were found for caregivers of female patients ($p<0.001$).

QOL and FEV1

We could not find any significant relevancy between FEV1 percentage of predicted and overall scores of QOL. ($p>0.05$) (Figure 1)

Table 2. Comparison of quality of life scores in caregivers of asthmatic patients.

Asthma severity	Step I	Step II	Step III	Step IV	P-Value
Total scores(Caregivers of male patients)	4.56	3.9	2.9		<0.001
Total scores(Caregivers of female patients)	5.74	3.9	3.5		<0.001
Activity(Caregivers of male patients)	5.74	4.5	3.38		<0.001
Activity(Caregivers of female patients)	5.9	4.15	3.6		<0.001
Emotion (Caregivers of male patients)	5.2	3.61	2.79		<0.001
Emotion(Caregivers of female patients)	5.59	3.7	3.5		<0.001

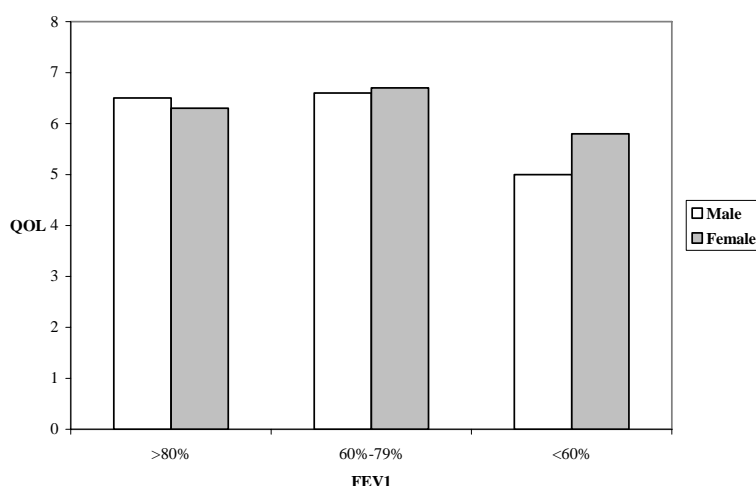


Figure 1. Comparison of FEV1 with QOL score in asthmatic patients ($p < 0.05$).

DISCUSSION

We could for the first time assess the spirit of therapy or "QOL" in asthmatic patients and their caregivers in Iran. It is less than two decades that QOL has been introduced to modern medicine and needs more attention.

Spirits of life and therapy are not separate from physical health. Results of this study showed that PAQLQ had validity and reliability. This questionnaire could measure changes in patients that their disease was unstable and differentiate them from stable patients. In comparison with other studies for example by Juniper and her colleagues in Canada in 1996, we found changes with score = 0.5 was significant and meaningful.¹³ In our study we also found that more severity of asthma is coincident with more disturbances of QOL. These disturbances that are in three domains of "Emotional", "Symptoms" and "Physical activities" have been shown in other studies.^{14,15} In boys the most disturbances between three main domains were, according to severity of asthma, for "Activity". In several studies that have been performed in adults QOL was more disturbed in females¹⁶ but such studies in children and young adults are very limited. Male gender is a risk factor for asthma in childhood and on the other hand ethnicity is also an important factor in incidence of asthma. Smaller airways and higher airway resistance and more field of activity in males than females may explain why boys have more disturbed life style than females. In New Zealand prevalence and mortality of asthma are more than other

countries. More studies are needed to assess differences of QOL in different ethnics. The results of our study were assessed of QOL in caregivers of patients. The first we could show validity, responsiveness and importance of items of PACQLQ in a pilot study. This questionnaire has been designed for the first time by E.F. Juniper in 1996. We could assess QOL of 113 main caregivers of asthmatic patients. Main caregivers were those who had spent at least more than 75% of their time caring for their patients. In our study all of caregivers were mothers. We found that with increment of asthma severity they will have more disturbances of QOL. Problems of patients usually reflect on family especially the mothers. Other studies have the same results.^{7,13} As asthmatic patients, more disturbances were in caregivers of male patients, perhaps because of two factors:

- 1) More disturbances of QOL in male patients
- 2) More emotional relationship between mothers and sons than daughters in Iranian families.

These results suggest that the specific problems associated with caring for a child with asthma are more closely related to general problems of looking after a sick child than we anticipative.

Other result of this study was assessment of relation between FEV1 (percent of predicted) with QOL. In other studies there has not been any relation between FEV1 (% predict) and QOL scores.¹⁶ FEV1 is a dynamic factor not a static factor. Degrees of obstructivity and reactivity of airways change with time, so a normal spirometry is not an enough testimony for good health of patients during the last

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week and vice versa. When we assess "QOL" of patients by a questionnaire not only we notice objective factors but also subjective items with personal center.^{1,13,17} Attention to an objective factor can not explain the QOL of a patient with a chronic disease.

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REFERENCES

1. Juniper EF, Guyatt GH, William A, Griffith LE. Determining a minimal important change in a disease-specific Quality of Life Questionnaire. *J Clin Epidemiol* 1994; 47(1):81-7.
2. Wake M, Hesketh K, Cameron F. Functional health status of children with diabetes. *Diabet Medicine* 2000; 17(10):700-7
3. Waters E, Stewart-Brown S, Fitzpatrick R. Agreement between adolescent self-report and parent reports of health and well-being: results of an epidemiological study. *J Paediatr Child Health* 2003; 29(6):501
4. Vogels T, Verrips G HW, Verloove-Vanhorick SP, Fekkes Kamphuis RP, Koopman HM, et al. Measuring health – related quality of life in children: the development of the TACQOL parent form. *OQL Res* 1998; 7(5): 457-65.
5. Raphael D, Rukholm E, Brown I, Hill–Bailey P, Donatol E. The quality of life profile – Adolescent Vesrion: background, description and initial validation. *J Adolesc Health* 1996; 19(5):366-75
6. Eisen M, Ware JA, Donald CA, Brook RH. Measuring components of children's health status. *Med Care* 1979; 17(6):902-21.
7. Ellen CP, Corinne L, Martin HY. Shared Vision: Concordance Among Fathers, Mothers, and Pediatricians About Unmet Needs of Children With Chronic Health Conditions. *Pediatrics* 2000; 105(Suppl 1):277-85
8. Starfeld B, Bergner M, Ensminger M, Riley A, Ryan S, Green B, et al. Adolescent health status measurement: development of the child health and illness profile. *Pediatrics* 1993; 91(2):430-5.
9. Hunt SM. Cross-cultural issues in the use of quality of life measures in randomized controlled trials. Oxford, UK: Oxford University Press, 1999: 51-68.
10. Landgraft J, Abetz L. Influences of sociodemographic characteristics on parental reports of children's physical and psychosocial well – being: early experiences with the child health questionnaire. In: Drotar D, editor. *Measuring health related quality of life in children and adolescents*. Mahwah, New Jersey: Lawrence Erlbaum Associated, 1998: 105-30.
11. Guyatt GH, Kinshar B, Jaeschke R. Measuring health status: what are the necessary measurement properties? *J Clin Epidemiol* 1992; 45(12):1341-5
12. Malo JL, Archeveque J, Trudeau C, d' Aquino C, Cartier A. Should we monitor peak expiratory flow rates or record symptoms with a simple diary in the management of asthma ? *J Allergy Clin Immunol* 1993; 91(3):702-9.
13. Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in the parents of children with asthma. *Qual Life Res* 1996; 5(1):35-46.
14. Svetlana S, Pljaskic K, Dragoslov V. Asthma Quality of life as a marker of disease severity and treatment evaluation in Scholl children. *Medicine and Biology* 2002; 9(2):175-80.
15. Riccioni G, Orazio D. Quality of life and clinical symptoms in asthmatic subjects. *J Asthma* 2004; 4(1):85-9.
16. Heidy N, Chan KS. Is the asthma Quality of life questionnaire a useful measure for low– Income asthmatics? *Am J Respir Crit Care Med* 1998; 158(4):1082-90.
17. Juniper EF, Guyatt GH, Feeny DH, Ferrie PJ, Griffith LE, Townsend M. Measuring quality of life in children with asthma. *Qual Life Res* 1996; 5(1):27-34.