Quality of life and psychological status of asthmatic children and their caregivers

Doctoral theses

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Introduction

If ever one was offered the elixir of eternal life, presumably the first question arising would be „what kind of a life that would be". (Forever young and healthy? In what financial circumstances? In what social status? With my beloved ones ore alone?) By weighing human life not only the length but also the quality of life (QoL) matters.

Socrates stated in the ancient time: „*We should put the highest value on living well and not living."*

Diseases and medical interventions can and do interfere with the length of life. According to the above, it is self-evident that we can only get a clear picture if we take into consideration the effects on quality of life as well, which is what health related quality of life addresses.

In health related quality of life studies the subject of health is the whole person – not only its body. This branch of quality of life studies focuses on subjective health, and emphasizes that „objective" health measures do not give a full picture of the patient and the disease. According to behavioral science quality of life is the complex of one person's physical and psychological measures, and also involves how a person feel itself healthy, and how much pleasure his health, activities and living his life gives.

In clinical practice quality of life focuses on how the short and long term effects of a disease interferes with the patient's physical well-being, activity, human connections, and mental health. Permanently impaired health can be tragic in many ways, as impacts do not only come from the disease itself (pain), but also the disease can hider every day work, social circumstances can also be influenced. On the whole it can be stated that a disease not only burdens the individual and the society by physical functional loss, but also affects the "felling of competency" in the other areas of living; notably deterring subjective quality of life; and can cause further deterioration in health status.

In 1948 WHO declared that "*Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*." Since then clinical studies and health services focus on quality of life issues.

Quality of life connects with health-behavior, and consequently with health services utilization and adherence to therapy, and through these being a stronger predictor of the success of therapy than objective symptoms.

The widely accepted definition of QoL was published by Schipper et al. in 1995: *„ the functional effects of an illness and its consequent therapy upon a patient, as perceived by the patient".*

Bronchial asthma through its symptoms interferes strongly with everyday lives if the patients, achievements of work and school, social and free time activities. At the same time causes

tension, fear and depressive symptoms. So quality of life of asthmatic patients is hindered in mostly all areas.

Depression prevalence amongst asthmatics is higher overall. Different studies resulted in a depression rate between 1-45%. Unfortunately this wide range makes drawing conclusions more difficult, but most authors vote for higher depression rate in asthma.

Anxiety symptoms are also higher amongst asthmatics, and can also result in higher morbidity of asthma.

Asthmatic children's asthma and psychiatric status of their caregivers can mutually interfere.

Depression, mania, substance abuse, and antisocial disorder were higher amongst relatives of asthma according to Wamboldt et al.

Aims

A. Short- and long-term quality of life of already grown-up childhood asthmatics

1) How are the grown-up childhood asthmatics who were treated at the Semmelweis University?
2) Do they have, and if yes how serious are their asthmatic symptoms, and how is their quality of life?
3) In which areas of life childhood asthma hinders them in the short- and long-run?
4) How does the possible deterioration of quality of life connect with their actual adult symptoms?

B. Quality of life, psychological status of asthmatic children

1) How does the disease of asthmatic children influence these children's quality of life and psychological status?
2) Is anxiety or depression higher amongst them?
3) How are these findings altered by the child's gender, age, asthma status, actual symptoms or obesity
4) Does the age of the onset of asthma interfere with these results?
5) To compare our findings with the international literature.
6) To compare our findings with children suffering from chronic renal disease.

C. Quality of life and psychological status of asthmatic children's caregivers

1) To study the burden of asthma on the QoL and psychological status of asthmatic children's caregivers.
2) What connection exists between the child's and caregivers' asthma, QoL, and psychological status?
3) Do caregivers' symptoms interfered by the child's current asthma symptoms, parental education, or gender difference?
4) To compare our findings with the caregivers of children suffering from chronic renal disease.

Patients and Method

A. Short- and long-term quality of life of already grown-up childhood asthmatics

A letter was sent to every recent adult patient over 30 years old who has been treated with bronchial asthma in childhood in the Semmelweis University First Department of Pediatrics. Their data was obtained from the patient-documentation. They were all discharged from the Department with the diagnosis of bronchial asthma. A letter has been sent to all identified 501 patients, in which they were asked to answer questionnaires about their current symptoms of asthma and asthma related short-term quality of life (Juniper Asthma Quality of Life Questionnaire, Hungarian validated version). Further assistance was not permitted.

Our patients were divided into symptomatic and symptom free subgroups. We measured the mean of the answers and confidence intervals of these subgroups, and studied their difference from the mean of the whole group.

B. Quality of life, psychological status of asthmatic children

In 2005 we enrolled 108 asthmatic children between the age of 7-17 (mean age: 11.75 years) who attended consecutively the outpatient clinic of the First Department of Pediatrics, Semmelweis University, Budapest. Asthma diagnosis was established by an asthma specialist. Treatment of the children's asthma was up-to-date according to the last published WHO GINA guidelines. Children were asked to complete the Hungarian validated version of the Child Depression Inventory (CDI), the Hungarian validated version (H.STAIC) of the Spielberger State Anxiety Inventory for Children (STAIC), the Juniper Pediatric Asthma Quality of Life Questionnaire (PAQLQ), and a symptom score. The questionnaires were completed according to

their official manuals. Patients filled in the questionnaires before the doctor's visit, in another room. Children could ask for help from a skilled person in completing the questionnaires.
The children's forced exspiratory volume in one second (FEV_1) was also measured with Custo Vit-M Spirometer (Custo Med GmbH), compared to the norms of Zapletal.
We used a group of 27 children with chronic renal disease treated at the same University clinic as controls.

C. Quality of life and psychological status of asthmatic children's caregivers

Caregivers of the asthmatic and renal children were asked to fill the Hungarian validated versions of the Juniper Pediatric Asthma Caregivers' Quality of Life Questionnaire (PACQLQ), the Spielberger Anxiety Inventory (STAI) and the short form of the Beck Depression Inventory (BDI).
The official manuals were followed at the questionnaire completion.

Results

A. Short- and long-term quality of life of already grown-up childhood asthmatics

- We received 152 answers from 105 (69%) male and 47 (31%) female patients with the age range of 31-55 years (median 37 years).
- Asthma started between 0.5-13 years (median 3.25).
- 91 patients (60%) were currently symptom free, 58 (38%) were symptomatic, 3 patients (2%) did not answer the question.
- Asymptomatics experienced their last symptoms between the age of 3-41 years (median=14 ys).
- Symptomatic patients belonged tot he following GINA classification group: 34 (58%) GINA I intermittent, 9 patients (15,6%) GINA II mild persistent, 5 patients (8,8%) GINA III moderate persistent, 5 patients (8,8%) GINA IV severe persistent. 5 patients did not give details (8,8%).

Short term quality of life

- Only few persons were severely limited by their disease. With the average increasing, (which means better state), the number of patients is exponentially increasing, most of them not experiencing any QoL decrease.

- Symptomatic patient reached an average of 5.28 points (CI=5.1-5.45), while their asymptomatic peers reached a better QoL with 6.8 points (CI=6.74-6.86).
- On the Juniper Asthma Quality of Life Questionnaire Symptomatic group experienced the biggest problem in the following area:
  - *"having to avoid a place or situation because of dust"* (4.19; CI=3.84-4.54),

statistically also problematic areas:

  - *"experiencing asthmatic symptoms because of the weather or air-pollution"* (4.38; CI=4.03-4.73).
  - *„disturbed by shortness of breath"* (4.55; CI=4.2-4.9),
  - *"difficult to exhale because of asthma"* (4.73; CI=4.38-5.08),

- Least problematic areas were:
  - *"concerned about medication"* (5.84; CI=5.49-6.19),
- Other relatively not hindered areas:
  - *"felt least frustrated as a result of their asthma"* (5.99; CI=5.64-6.34),
  - *"avoid or limit going outside because of the weather or air pollution"* (5.84; CI=5.49-6.19).
- Most problematic areas of the symptomatic patients:
  - *"frequent need to clear throat"* (6.42; CI=6.37-6.47)
- Other problematic areas:
  - *"avoid a situation or environment because of dust"* (6.52; CI=6.47-6.57),
  - *"asthma symptoms as a result of being exposed to dust"* (6.52; CI=6.47-6.57) and
  - *"Avoid a situation or environment because of cigarette smoke"* (6.56; CI=6.51-6.61).

Long term quality o life

- Only a few persons were severely limited by their disease. By the average increasing, (which means better state), the number of patients is exponentially increasing, most of them not experiencing any QoL decrease.
- Patients were most hindered in *„doing sports"*, considerable decrease was found in *„choosing a career"*, and *„choosing a place of living"*.
- Least hindered are was *„religious, spiritual life"*.
- Areas of low influence were *„family life, human relations"*, „social life", *„choosing a partner"*, and *„making friendships"*.
- Symptomatic patients reached 6.13 (CI=5.94-6.32) on the LTAQLQ questionnaire, while their asymptomatic peers scored statistically higher with 6.64 (CI=6.54-6.74).
- Amongst the symptomatic patients, the most limited area was:

- *„Sports”* 5.16 (CI=4.71-5.61)

- They were least limited in their:
  - *„Making friends”* 6.58 (CI=6.38-6.78)
  - *“Religious life”* 6.72 (CI=6.47-6.97)
- The most problematic area for the symptom free patients was also:
  - *“Sports”* 6.11 (CI=5.83-6.39).
- The least problematic items:
  - *“Spiritual life”* 6.94 (CI=6.88-7.00)
  - *“Eating, selecting meals”* 6.89 (CI=6.82-6.96).

B. Quality of life, psychological status of asthmatic children and children with renal disease

Asthma severity and actual symptoms

- Children started to have asthma between 0,5-14 years of age (median=3 ys).
- 23 children (21%) were intermittent, 40 children (37%) mild persistent, 43 children l(40%) moderate persistent, 2 children (2%) were severe persistent asthmatics.
- FEV1% proved to be less than 80% in 5 children (5%), between 80-100% 53 children (49%); and 36 children (33%) above 100% 14 children (13%) could not perform this test. Median of the FEV1% was 87 (49-131 range).
- Our patients were relative symptom free on the preceding week, scoring 1.05±1.74 points where the maximum is 9.

Depression, anxiety, quality of life results

Depressive symptoms

- On the CDI questionnaire the maximum is 54 points, higher value meaning more depressive symptoms. Median of the asthmatic children was 9 points (min.0, max.29 points).
- Asthmatics in all age groups had less depressive symptoms than the population average measured by Rózsa et al; but this finding was only significant in pre-adolescent boys (p=0.032).
- As it can be detected even in the healthy population, asthmatic teenager girls showed more depressive symptoms, although these fine differences did not prove to be significant.
- Depressive symptoms of the children with renal diseases did not differ from the asthmatics’. Only teenager boys have less depressive symptoms than the healthy controls.

Anxiety symptoms

- Ont he H.STAIC questionnaire the maximum is 60 points, higher value meaning more anxiety symptoms. Median of the asthmatic children was 31.16±4.61 points (20-48 range); boys reaching 30.64±4.29, girls 32.67±5.27 points. The Hungarian population average is 30.37±4.14 for boys and 30.88±3.77 for girls, according to Spielberger and Sipos.
- Asthmatic patients did not show more anxiety symptoms than their healthy peers. No difference was found in the pre-adolescent versus adolescent groups.
- Extremely significant difference was found when compared to the renal control group; children with renal diseases had higher anxiety scores.

Quality of life

- Children with asthma scored 6.18±1.00 (2.87-7.00) on the PAQLQ quality of life questionnaire, where the best score is 7.00.
- Symptomatic children reported poorer QoL than the asymptomatics ($p<0,0001$).
- Adolescent asthmatic girls have the worst quality of life.
- Boys reach better quality of life scores as they grow older ($p=0.02$).
- Girls in adolescence have a tendency of decreasing quality of life, although the difference is not significant.
- Girls in adolescence have a tendency of decreased quality of life ($p=0.013$).

Psychological symptoms according to disease severity and according to age

- We divided our patients into intermittent asthmatic and persistent asthmatic (mild+moderate+severe) subgroups. Depression, anxiety and quality of life were not statistically different between the intermittent and persistent groups.
- Depression and anxiety were not affected by the current asthma symptoms. Children in the currently symptomatic subgroup experienced poorer quality of life ($p=0.00061$) than the symptom free subgroup.
- There was no significant age specific difference in depression, anxiety or quality of life scores according to age in the pre-adolescent and adolescent subgroups.

Obesity

- Asthmatic children had a BMI average of 19.29 ± 4.10 (average ± SD). 85% of the patients had normal values (BMI less than 25); and 7% were obese (BMI higher than 25).
- Overweight and obese asthmatics had a significantly poorer QOL than their normal weighted peers. We did not find any connection in terms of depression or anxiety.

Age at the onset of asthma

- Our patients started having asthma symptoms between the age of 0.5-14 years (median=3 ys). Quality o life was significantly poorer to those patients whose asthma started before the age of 3 years: 6.11 (2.91-7.00) versus 6.71 (2.87-7.00) (p=0.0337).
- We found no connection between the age onset and depression or anxiety.

Other allergic diseases

- We have not found any difference regarding depression, anxiety, quality of life between the group of patients having no other allergies, or having one or more other allergies (allergic rhinitis, atopic dermatitis, allergic conjunctivitis, food allergy, other).
- 20% of our patients did not show positive skin prick tests, 80% had at least on e positive reaction (trees, grass, ragweed, Artemisia, dust mite, alternaria, cat, dog, other animals, and feather).
- We did not find any difference concerning depression, anxiety, quality of life between the two groups of positive and negative skin prick test.

Night symptoms

- We have found that patients with night symptoms had poorer QOL than their asymptomatic peers: 5.54 (3.04-6.21) versus 6.69 (2.87-7.00), (p=0.0002).
- Difference in depression was just below significance between the two groups. No difference was found regarding anxiety.

Daytime symptoms

- We have found that patients with daytime symptoms had poorer QOL than their asymptomatic peers: 6.26 (2.87-6.95) versus 6.73 (3.82-7.00), (p=0.0003).
- No difference was found regarding anxiety and depression.

Does the presence of anxiety mean other psychological symptoms as well?

- We divided our patients into two subgroups considering weather their anxiety result was higher or below than the Hungarian population average. Patients with higher anxiety points reported higher depression points as well: 10.5 (3-29) versus 7.00 (0-7.00); (p<0.0001).
- Amongst the higher anxiety group 58% had also higher depression points a well; in the other group only 19%; (p<0.0001, OR=6.14).
- Higher anxiety symptoms did not come with QOL decrease.

Does the presence of depression mean other psychological symptoms as well?

- We divided our patients into two subgroups considering weather their depression result was higher or below than the Hungarian population average. Patients with higher depression points reported higher anxiety points as well: 33.00 (28-48) versus 30.00 (20-30) ($p=0.0002$).
- Patients with higher depression points reported higher QOL points as well: 6.21 (2.93-7.00) versus 6.69 (2.87-7.00); ($p=0.02$).
- Amongst the higher depression group 81% had also higher anxiety points a well; in the other group only 39% ($p<0.0001$, OR=6.74).
- The renal control group did not show any connections between depression and anxiety.

Does the presence of poorer QOL mean other psychiatric symptoms as well?

- We compared the group of highest QOL results (>6.5 points) with the group of lower QOL points (≤ 6.5). Even a decrease of 0.5 points comes with significantly higher depression and anxiety points. The depression median of the lower QOL group is 11.00 (2.00-29.00); anxiety points: 32.00 (21.00-48.00). Maximal QOL group scored a depression point of: 7.00 (0.00-24.00); anxiety points: 30.5 (20.00-38.00), corresponding p scores: 0.0042 and 0.018 respectively.

C. Quality of life and psychological status of asthmatic children's caregivers

- Asthmatic caregivers' age was 37 years (28-70), 19 male (39; 30-65 ys) and 79 female (36; 28-70 ys). Ten teenagers arrived to the visit without companion.
- Renal children's caregivers' age was 36 years (24-55), 7 male (24; 45-52 ys) and 20 female (29; 35.5-55 ys).
- Difference is not significant between CAC and CRC according to age.

Caregivers' depression

- Caregivers of asthmatic children scored 7.73±6.69 SD points on the Beck Depression Inventory. We compared it with the results of the 18-44 year old national population (NP) (5.24±7.43 SD); measured by Kopp et al.
- Caregivers of asthmatic children had significantly more depressive symptoms than their normal age specific peers ($p<0.01$); the prevalence of depressive symptoms is 33%.
- Caregivers of children with renal disease also experienced more depressive symptoms (9.61±7.43 SD) than the healthy population, but the difference between the two groups of caregivers with chronic diseases did not prove to be significant.

- We divided the caregivers of asthmatic children into two subgroups according to their BDI results. We compared the ones with depressive symptoms higher than the population average (5.24) to the ones lower than the average. Caregivers with more points on the BDI than the population average also have more anxiety symptoms, but their quality of life is not significantly different.
- Depressive symptoms were neither connected to the children's psychological symptoms nor quality of life.

Asthma severity and symptoms, gender differences, level of education

Caregivers' depression and asthma severity

- We examined CAC's symptoms according to their children's asthma severity of GINA 2004. As this study was conducted in 2005, the above was the most up to date classification available. We created two subgroups. The first one included intermittent and mild persistent; the second included moderate and severe persistent asthmatics.
- CAC's depressive symptoms were not connected to their child's asthma severity.
- No difference was noticed even when comparing the four GINA subgroups.

Caregivers' psychological status according to their children's asthma symptoms

- We divided the asthmatic children into two subgroups according to the presence or absence of asthma symptoms during the previous week, and examined their caregivers' depressive symptoms. Caregivers, whose children were symptomatic at the time of the study, did not have more depressive symptoms than the ones with symptom-free children.

Depressive symptoms, gender differences

- According to C. Csoboth, depressive symptomatology is represented amongst 30.7% of women and 25.6% of men in the Hungarian population, using the short version of the BDI in their study. We investigated the gender differences in both of the caregivers' groups.
- Amongst asthmatic children's caregivers at least mild depressive symptoms were represented amongst 39% of men, and 33% of women. Gender difference in depressive symptom level was not significant, despite observations in the normal Hungarian population.
- Amongst caregivers of renal children, depressive symptoms were represented in 14% of males and 50% of females. Gender difference was significant. ($p=0.05$)
- Significant difference was also observed between male asthmatic and renal caregivers; albeit difference was not significant between the female peers.

Depressive symptoms, level of education

- We also studied the CAC depressive symptoms according to their education level. The first subgroup consisted of maximum elementary school graduates, the second one of skilled labour, the third of secondary school, and the fourth of graduate school degree. No difference was found between the four educational groups in the number of depressive scores.

Consequences

A. Short- and long-term quality of life of already grown-up childhood asthmatics

- We found that 40% o grown up asthmatics still have symptoms, they experienced worse quality of life than the asymptomatic group. Even a couple of asthma attacks a year influences the patients' every day quality of life.
- Quality of life of he currently asymptomatic patients is also not maximal, due to the allergen avoidance measures.

B. Quality of life, psychological status of asthmatic children and children with renal disease

- Asthmatic children experience less depressive score than their healthy peers, but this phenomenon is only significant in pre-school children. Asthmatic children also do not show higher anxiety scores than their healthy peers.
- Asthmatics' anxiety points are less than the results of the renal children, but their depression points did not differ.
- Asthmatic teenager girls experience the worst quality o life.
- Prevalence o psychological symptoms did not depend from the asthma severity score,.
- With our results we added arguments to the fact that in asthma subjective and objective symptoms are independent factors even in childhood.

C. Quality of life and psychological status of asthmatic children's caregivers

- We proved that depression score is higher in both of the asthmatic and renal caregivers than the Hungarian population average. The difference between the score of the two chronic illness groups was not significant.

D. Lessons learned

1, Even up to date care of asthma ends up with quality of life deterioration after years or decades.

2, Thorough, patient centered and personal asthma care results in no anxiety or depression score elevation.

Asthmatic teenage girls deserve focused care considering their worst QOL results.

4, In Hungary, with the widely accessibility of drugs means better status for patients; and this might lead to a better psychological status.

5, Due to the higher prevalence of depression amongst asthma caregivers it is also worth to focus on their problems as well during asthma care, and when a diagnosis is suspected offer psychiatric help.

Publications

Publications directly connected to the dissertation

Articles

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