The difference between the reports from asthmatic children and their parents about the effect of asthma on their quality of life in pediatric hospital-Benghazi-Libya

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Abstract

Introduction: Childhood asthma is a serious health problem that results in impairment of physical and social life of the affected children.

Objective: The current study identifies the effect of asthma on asthmatic children quality of life and also to assess the differences between child’s and parents’ report about the effect of the asthma on the child's physical health, child's emotional health and child's activity.

Method: A cross-sectional, descriptive, quantitative study was carried out where about Sixty-four participants of asthmatic children with their parents that were attached at Pediatric Hospital in Benghazi have been recruited and asked to complete Children of Health Survey for Asthma (CHSA) instruments.

Results and Conclusion: The results showed that asthma relatively affects children’s physical health, activities and emotional health. Also, the results showed that there were significant differences in child's and parent report regarding the effect of asthma in child's quality of life.

Introduction:

Asthma is the most common chronic health condition in childhood, with an estimated worldwide prevalence of 11.6% in 6- to 7-year-old children and 13.7% in 13- to 14-year-old adolescents [1]. Asthma is defined as a chronic inflammatory disease of the airways, it is characterized by episodic exacerbations of shortness of breath, coughing, wheezing, and chest tightness, which may be life threatening and are a major cause of hospitalizations among pediatric patients. Additionally, dependence on medication, sleep disturbances, daytime fatigue, and school/work absenteeism and underachievement may also impair the quality of life (QoL) of children and adolescents and their families[2]. The ultimate goal of asthma treatment is to achieve and maintain clinical control and reduce future risks to the patient. To reach this goal in children with asthma, ongoing monitoring is essential[3]. QoL was formally defined by the World Health Organization Quality of Life (WHOQOL) Group, in 1994, as “a person’s perception of his/her position in life within the context of the culture and value systems in which he/she lives and in relation to his/her goals, expectations, standards, and concerns” [4]. The World Health Organization has defined the term health related quality of life as the individual’s perception of their position of life in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns[5]. Asthma might have physical, emotional and psychosocial impact on children’s lives[6]. Asthma is a chronic respiratory disease that adversely

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affects different aspects of quality of life (QoL) [7]. Childhood asthma is common in Libya and associated with repeated school absenteeism and hospital admission. So, there is a need to conduct a study in Libya to assess the effect of asthma on asthmatic children, and to present the difference of child’s and parent’s report about the effect of asthma on their lives.

Methodology:
A cross-sectional, descriptive, quantitative study was carried out to evaluate the effects of asthma on physical health, activities, and emotional health of asthmatic children and their parents. After getting ethical approval and informed consent, both version of Children Health Survey for Asthma (CHSA) instrument was translated to Arabic language. After that Sixty-four participants of male and female asthmatic children with their parents that were attached at pediatric hospital in Benghazi have been recruited and asked to complete CHSA instruments. Data collection for the study were conducted from January to October 2020. This study excluded children less than 6 years old, and asthmatic children who were hospitalized i.e only those on routine appointment from out-patient pool.

CHSA is one of the instruments that targeted the asthmatic children, developed by American Academy of Pediatrics (AAP) Department of Research. It was constructed to enhance and advance health services research related to children and their families. It is self-administered measure and has two versions for parents (CHSA) and for asthmatic children (CHSA-C). CHSA instruments are an asthma-specific instruments that has items computed in 3 domains including child’s physical health, child’s activities, and child’s emotional health and Computed scale scores were transformed as the following equation:

\[ \text{scale} = \frac{(\text{mean of all items})}{4} \times 100 \]

The scale scores ranged from 0 - 100. Higher scores indicated better health status or more positive outcomes. The data was analyzed by excel sheet [8]. The demographic profile of all participants and medical data of asthmatic children were described using percentages and frequencies for the categorical variables, while means and median for the continuous variables. To assess the item analysis, basic descriptive statistics such as frequency and percentage of responses of each item were examined.

Results:
Demographic data for asthmatic children n=64
Table (1) shows the demographic data for the asthmatic children and their parents. The mean of the children's age was 11, and the gender was 50% girl and 50% boy. All the children do not smoke. About 51% of them said that they have a smoker in their house. 31% of them do not have pets. About 82% of them have diagnosed by asthma during the last five year. About 71% of them don not hospitalize due to asthma. About 93% of the children do not have other disease. 95% of them use salbutamol inhaler as a management disease. 49% of them have moderate asthma according to the physician that routinely follow. The table shows also the mean of the parent's age which was 41.

Child's report
Physical health items (n=7) were reported in table (2) which shows that about of 28.1% of the children had shortness of breath, 32.8% had wheezing and cold, and about 35.9% of them had difficulty in sleeping.

Child's activity items (n=6) were reported in table (3) which shows that about 29.6% of the children did not participate in school gym classes, 64.2% did not play at friends' house, and the did not do things that need little energy.

Emotional health items (n=12) were reported in table (4) which shows that about 31.3% of the children feel frustrated about having asthma, 34.3% of them feel frustrated that they can not do some things because asthma, 43.7% of them upset about having asthma and 35.9 % of them upset by having to use asthma treatment.

Parent report
Parent report about child’s physical health was computed in 15 items which reported in table (5). Parents reported that their asthmatic children had better physical health than their children themselves. Table (6) shows parent report about child's emotional health which computed in 5 items where the parent reported that their asthmatic children
had better emotional health than their children themselves. Table (7) shows parent report about child’s activities which computed in 5 items.

**Differences between parent and child report**

This part of the result included scale computing for core items of both child and parent version of CHSA. The results addressed the objective of this study, which was to present the difference of child’s and parent’s report about the effect of asthma on their lives. Computed scale scores were transformed by the following equation (scale = ((mean of all items-1)/4)*100)). The scale scores ranged from 0 - 100. Higher scores indicated better health status or more positive outcomes. The result shows that there are differences in all domain between asthmatic children and their parents. Parents reported that their asthmatic children had better physical health, activity, and emotional health than children themselves.

**Tables and figure**

**Table 1:-** Demographic Data.

| Asthmatic children (n = 64) | n (%) |
|-----------------------------|-------|
| **Age (years old)**        |       |
| Mean                        | 11.0  |
| Median                      | 10.0  |
| Min: 6 Max: 16              |       |
| **Gender**                  |       |
| Boy                         | 32 (50%) |
| Girl                        | 32 (50%) |
| **Do you smoke?**           |       |
| No                          | 64 (100) |
| Yes                         | 0 (0) |
| **Does anyone in your house smoke?** |       |
| Yes                         | 33 (51.5%) |
| No                          | 31 (48%) |
| **Do you have pets?**       |       |
| No pets                     | 20 (31%) |
| Cat                         | 23 (35%) |
| Dog                         | 9 (14%) |
| Birds                       | 10 (15.6%) |
| **Child’s grade in the school** |       |
| Primary class 1             | 5 (7.8) |
| Primary class 2             | 7 (10.9) |
| Primary class 3             | 3 (4.7) |
| Primary class 4             | 15 (23) |
| Primary class 5             | 9 (14) |
| Primary class 6             | 4 (6.2) |
| Primary class 7             | 6 (9.3) |
| Primary class 8             | 6 (9.3) |
| Primary class 9             | 6 (9.3) |
| Secondary class 1           | 3 (4.6) |
| **Diagnosed period of asthma (year)** |       |
| Mean                        | 2.5   |
| Median                      | 2.0   |
| Min: 1 Max: 7               |       |
| 0 - 5 years                 | 52 (82.2) |
| 6 - 10 years                | 12 (18.7) |
| More than 10 years          | 0 (0) |
| Missing                     | 0 (0) |
| **Last hospitalization due to asthma (month)** |       |
| Mean                        | 2     |
| Median                      | 1.0   |
| Min: 1 Max: 2               |       |
Other disease beside asthma

- No hospitalization: 46 (71.8)
- 1 month ago - 1 year ago: 9 (14.0)
- 2 years ago - 3 years ago: 2 (3.1)
- More than 4 years ago: 0 (0)
- No other disease: 60 (93.3)
- DMT1: 2 (3.1)

Medication for asthma management

- Salbutamol inhaler: 61 (95.2)
- Zaditen+ salbutamol: 2 (3.4)

Inhalational devices for asthma management

- No devices: 22 (34.3)
- Aerochamber: 6 (14)
- Home nebulizer: 6 (3.3)
- Mild: 38 (21.1)
- Moderate: 89 (49.5)
- Severe: 26 (14.4)
- Missing: 27 (15.0)

Child asthma severity according to lung function (PEFR)

- No devices: 22 (34.3)
- Aerochamber: 6 (14)
- Home nebulizer: 6 (3.3)
- Mild: 38 (21.1)
- Moderate: 89 (49.5)
- Severe: 26 (14.4)
- Missing: 27 (15.0)

Is there anything else you would like to tell us about what it’s like for you to live with asthma?

- Answered: 15 (8.3)
- No comment: 165 (93.3)

### Table 2: Children Report About Their Physical Health.

| How much of the time have you had any of these things because of your asthma? | None of the time (5) | Little of the time (4) | Some of the time (3) | Most of the time (2) | All of the time (1) | Mean |
|---|---|---|---|---|---|---|
| a- Shortness of breath | 8 (12.5) | 16 (25) | 14 | 8 (12.6) | 18 | 2.81 |
| b- Tightness in the chest | 12 | 16 (25) | 14 (21.8) | 2 (3.1) | 20 | 2.96 |
| c- Wheezing without a cold | 18 (18.8) | 16 (25) | 14 (21.8) | 6 (9.4) | 30 (46.8) | 3.03 |
| d- Cough | 9 (14.1) | 11 | 14 (21.8) | 14 (21.8) | 26 (40.6) | 2.85 |
| e- A cold that won't go away | 9 (14.1) | 17 (27.3) | 20 (31.3) | 15 (23.4) | 13 | 2.87 |

Parent (n=64)

| Age of parent | Mean | Median |
|---|---|---|
| 41 | 39 |

| Gender of parent | Male | Female |
|---|---|---|
| 35 (54.68) | 29 (45.3) |

| Parents Education | Primary class 8 | Secondary class1 |
|---|---|---|
| Mother | 12 (18.7) | 6 (9.3) |
| Father | 22 (34.3) | 25 (39.0) |

| Marital status | A high school or Equivalent diploma | Institute | Professional certificate | Bachelor | Postgraduate | I do not know |
|---|---|---|---|---|---|---|
| Married | 62 (96.8) | 0 (0.0) | 2 (3.1) | 1 (1.56) | 3 (4.6) | 15 (23.4) |
| Divorced | 0 (0.0) | 2 (1.1) | 12 (18.7) | 25 (39.0) | 0 (0.0) | 6 (9.3) |
| Widow | 0 (0.0) | 3 (4.6) | 1 (1.56) | 2 (3.1) | 0 (0.0) | 165 (93.3) |
f- Wheezing with a cold  
g- Difficulty sleeping

| How much did asthma keep you from doing these things? | Not at all (5) | A little bit (4) | Some (3) | A lot (2) | Totally (1) | Mean |
|-------------------------------------------------------|----------------|-----------------|-----------|-----------|-----------|------|
| n (%)                                                 | n (%)          | n (%)           | n (%)     | n (%)     | n (%)     |      |
| a. School gym classes                                 | 4 (6.2)        | 14 (21.8)       | 12 (18.8) | 15 (23.4) | 19 (29.6) | 2.51 |
| b. Sports or running outside                          | 8 (12.5)       | 14 (21.8)       | 15 (23.4) | 12 (18.8) | 41 (64.2) | 2.85 |
| c. Playing at friends’ houses                         | 5 (7.8)        | 3 (4.6)         | 10 (15.6) | 5 (7.8)   | 10 (15.6) | 1.84 |
| a. Things that use a lot of energy                    | 7 (10.9)       | 8 (12.5)        | 23 (35.9) | 16 (25)   | 10 (15.6) | 2.78 |
| b. Things that use some energy                        | 8 (12.5)       | 7 (10.9)        | 14 (21.8) | 20 (31.3) | 15 (23.4) | 2.57 |
| c. Things that use a little energy                    | 12 (18.8)      | 1 (1.6)         | 2 (3.1)   | 8 (12.5)  | 41 (64.2) | 1.98 |

Table 3: Children Report About Their Activity.

| How much of the time did these things describe you because of your asthma? | None of the time (5) | Little of the time (4) | Some of the time (3) | Most of the time (2) | All of the time (1) | Mean |
|--------------------------------------------------------------------------|---------------------|------------------------|----------------------|----------------------|---------------------|------|
| n (%)                                                                    | n (%)               | n (%)                  | n (%)                | n (%)                | n (%)               |      |
| a. I am frustrated about having asthma.                                  | 4 (6.2)             | 5 (7.8)                | 11 (17.2)            | 24                    | 20                   | 2.20 |
| b. I feel left out by other people.                                      | 35 (54.6)           | 7 (10.9)               | 5 (7.8)              | 13                    | 10                   | 3.13 |
| c. I am sad.                                                             | 26 (40.6)           | 11 (17.2)              | 6 (9.4)              | 6 (9.4)               | 13                   | 3.35 |
| d. I am embarrassed about having to use an inhaler in school.            | 25 (39.1)           | 10 (15.6)              | 15 (23.4)            | 6 (9.4)               | 13                   | 2.65 |
| e. I am frustrated about having to use asthma treatments.                | 8 (12.5)            | 8 (12.5)               | 5 (7.8)              | 21                    | 17                   | 2.12 |
| f. I am frustrated that I can’t do some things because of asthma.        | 7 (10.9)            | 3 (4.7)                | 11 (17.2)            | 17                    | 22                   | 2.11 |
| g. I am upset about having asthma.                                       | 6 (9.4)             | 35 (54.6)              | 5 (7.8)              | 28                    | 28                   | 2.53 |
| h. I am upset by having to use asthma treatments.                        | 11 (17.2)           | 34 (54.3)              | 12 (18.5)            | 23                    | 23                   | 2.32 |

Table 4: Children Report About Their Emotional Health.

| How much do you agree or disagree with these things about asthma?         | Strongly disagree (5) | Disagree (4) | Not sure (3) | Agree (2) | Strongly agree (1) | Mean |
|--------------------------------------------------------------------------|-----------------------|--------------|--------------|-----------|-------------------|------|
| n (%)                                                                    | n (%)                 | n (%)        | n (%)        | n (%)     | n (%)             |      |
| a. My asthma causes stress in my family.                                 | 5 (7.8)               | 23 (35.9)    | 6 (9.4)      | 10        | 20                | 2.73 |
| b. I am frustrated that other people don’t understand what it is like to have asthma. | 11 (17.2)             | 12 (18.5)    | 8 (12.5)     | 18        | 5 (7.8)           | 3.25 |
| c. Sometimes I get angry and ask "why is this happening to me?"          | 11 (17.2)             | 22 (34.3)    | 8 (12.5)     | 18        | 13                | 2.91 |
d. I know which medicines to take for my asthma.

Table 5: Parent Report About Child's Physical Health.

| How much of the time has your child had any of the following due to asthma? | None of the time (5) | Little of the time (4) | Some of the time (3) | Most of the time (2) | All of the time (1) | Mean |
|---|---|---|---|---|---|---|
| a. Shortness of breath | 16 (25) | 24 (37.5) | 19 (29.6) | 3 (4.7) | 2 (3.1) | 3.72 |
| b. Tightness in the chest | 18 (28.1) | 25 (39.1) | 15 (23.4) | 4 (6.2) | 2 (3.1) | 3.78 |
| c. Wheezing without a cold | 14 (21.9) | 24 (37.5) | 22 (34.3) | 1 (1.5) | 3 (4.6) | 3.71 |
| d. Cough | 12 (18.7) | 21 (32.8) | 16 (25) | 13 (20.3) | 2 (3.1) | 3.37 |
| e. A cold that won't go away | 6 (9.4) | 24 (37.5) | 19 (29.6) | 13 (20.3) | 2 (3.1) | 3.30 |
| f. Wheezing with a cold | 12 (18.7) | 37 (57.8) | 1 (1.5) | 2 (3.1) | 12 (18.7) | 3.51 |
| g. Difficulty sleeping | 13 (20.3) | 26 (40.6) | 7 (10.9) | 10 (15.6) | 3.31 |

- During the past 2 weeks, how often did your child have each of the following that may have been due to asthma medicines?

| How much of the time did each of the following statements describe your child due to asthma? | None of the time (5) | Little of the time (4) | Some of the time (3) | Most of the time (2) | All of the time (1) | Mean |
|---|---|---|---|---|---|---|
| a. Rapid heart rate | 24 (37.5) | 19 (29.6) | 16 (25) | 5 (7.8) | 0 (0) | 3.92 |
| b. Headache | 30 (46.8) | 27 (42.1) | 3 (4.6) | 2 (3.1) | 2 (3.2) | 4.21 |
| c. Upset stomach | 36 (56.2) | 24 (37.5) | 3 (4.6) | 1 (1.5) | 0 (0) | 4.42 |
| d. Tightness in the chest | 22 (34.3) | 22 (34.3) | 17 (26.5) | 2 (3.1) | 1 (1.5) | 3.92 |
| e. Irritable or fussy | 26 (40.6) | 27 (42.1) | 4 (6.2) | 2 (3.1) | 5 (7.8) | 4 |
| f. Fatigue | 13 (20.3) | 24 (37.5) | 25 (39.1) | 0 (0) | 2 (3.2) | 3.68 |
| g. Difficulty paying attention | 18 (28.1) | 35 (54.6) | 8 (12.5) | 0 (0) | 3 (4.6) | 3.98 |
| h. Difficulty sleeping at night | 17 (26.5) | 25 (39.1) | 20 (31.2) | 0 (0) | 2 (3.2) | 3.80 |

Table 6: Parent Report About Child's Emotional Health.

| How much of the time did each of the following statements describe your child due to asthma? | None of the time (5) | Little of the time (4) | Some of the time (3) | Most of the time (2) | All of the time (1) | Mean |
|---|---|---|---|---|---|---|
| a. Is frustrated about having asthma | 25 (39.1) | 16 (25) | 10 (15.6) | 6 (9.4) | 7 (10.9) | 3.68 |
| b. Is frustrated having to rely on asthma treatments | 23 (35.9) | 17 (26.5) | 11 (17.2) | 9 (14.1) | 4 (6.2) | 3.68 |
| c. Is frustrated by having to limit activities because of asthma | 27 (42.1) | 21 (32.8) | 0 (0) | 8 (12.5) | 7 (10.9) | 2.50 |
| d. Is upset about having asthma | 29 (45.3) | 19 (29.6) | 0 (0) | 16 (25) | 0 (0) | 3.96 |
| e. Is upset by having to take asthma treatments | 27 (42.1) | 22 (34.3) | 12 (18.7) | 3 (4.6) | 0 (0) | 4.09 |

Table 7: Parent Report About Child's Activity.

| How much was your child limited from participating in the following activities because of asthma? | Not limited (5) | Limited a little (4) | Limited some (3) | Very limited (2) | Totally limited (1) | Mean |
|---|---|---|---|---|---|---|
| n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) |
Discussion:-
Asthma is the most common chronic disease in children, causing burden on health system. In recent years, prevalence of asthma symptoms became globally increased in children and adolescents, particularly in Low-Middle Income Countries [1]. Asthma in children related to low quality of life especially in limitation of physical activities and study performance. The implementation of strategies aimed at early detect asthma thus providing access to the proper treatment has been shown to effectively reduce the burden of the disease [1]. The current study identified the effect of asthma on asthmatic children quality of life and found that asthma relatively affects children’s physical health, activities and emotional health.

Most QoL studies of chronic diseases in children depends on questionnaires completed by the parents. For infants and toddlers, information on symptoms and treatment of allergic disease must be retrieved from the parents, but as the children grow older and more independent, parental reporting becomes less effective [9]. As accurate data are important for improving QoL for patient and increase asthma management, some studies examined the agreement between parent and child responses, and good agreement was found for physical activities and symptoms domains [10,11]. On the other hand, poor agreement was found for social, emotional domains, and cognitive functioning [12]. Previous study used English versions of CHSA and found that child’s and parent’s reports regarding child's physical health, activity and emotional health differs in key areas. In order to that further studies are needed to show if there are differences in child’s and parent’s reports [13]. In the present study, the findings showed a significant difference between children’s and parents’ reports in the children’s activities, emotional and physical health domains. However, the result in the present study showed that the parental rating of activities, emotional health and physical health were significantly higher than those of child respondents. Also, another study which supported the results of the present study showed that children with cancer feel that they have greater control over their treatment compared to their parents’ perception and the parents have more pessimistic views of the illness than their children [14]. Application of these translated questionnaires is important to describe the health status of pediatric populations, examining the outcomes of various conditions and treatment methods, and potentially improving clinical decision-making by capturing the broader impact of disease and treatment based on child and parent perspectives.

| Activity                                      | Parent Report (%) | Child Report (%) |
|-----------------------------------------------|-------------------|------------------|
| a. School gym classes                         | 25 (39.1)         | 14 (21.9)        |
| b. Sports or running outside                  | 21 (32.8)         | 18 ((28.1)       |
| a. Very "strenuous" activities                | 12 (18.7)         | 15 (23.4)        |
| b. Moderate activities                        | 14 (21.9)         | 30 (46.8)        |
| c. Mild activities (such as walking)          | 50 (78.1)         | 9 (14.1)         |
|                                              | 20 (31.2)         | 14 (21.9)        |
|                                              | 9 (14.1)          | 2 (3.2)          |
|                                              | 14 (21.9)         | 4 (6.2)          |
|                                              | 1 (1.5)           | 1 (1.5)          |
|                                              | 3.77              | 3.59             |
|                                              | 3.18              | 3.72             |
|                                              | 4.62              |                  |

Figure 1: Difference Between Parent and Child Report.
Conclusion:-
Asthma is a chronic respiratory disease that adversely affects different aspects of quality of life, and childhood asthma is common in Libya. So, this study highlights on the effect of asthma on their quality of life and also to assess the differences between child’s and parents’ report about the effect of the asthma on the child’s physical health, child’s emotional health and child’s activity. The present results showed that asthma relatively affects children’s physical health, activities and emotional health. Also, the results showed that there were significant differences in child's and parent report regarding the effect of asthma in child's quality of life.

Recommendation:-
It is recommended that the quality of children should be assessed and observed during clinic visits for a better holistic approach and effective improvement of outcome. Further researches are needed to study the risk factors leading to poor asthma control. Additional studies on the performance of the Arabic versions of CHSA with various populations of asthmatic children, especially those underserved and at-risk, are needed.

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