

Quality of Life among Children with Bronchial Asthma and Their Families' Caregivers

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Abstract: Bronchial Asthma (BA) is a serious, global, and chronic health problem among children. Worldwide, the prevalence of bronchial asthma, its related morbidity and mortality are increasing. It leads to school absenteeism, frequent emergency admission and hospitalization. Bronchial Asthma was impairing not only the quality of life of the children but also their families' caregivers. Aim of the study: determine quality of life among children with bronchial asthma and their families' caregivers. Settings: The study was conducted at pediatric outpatient, inpatient departments and pediatric allergy clinic at Damanhur Medical National Institute. Subjects: A convenient sample of 100 children with bronchial asthma and their caregivers. Tools: three tools were used for data collection. Socio-demographic characteristics of children with BA and their caregivers and children's clinical data structured interview schedule tool, Pediatric Asthma Quality of life Questionnaire with Standardized Activity (PAQLQS) and Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ) tool. Results: The highest percent of children exhibited low quality of life level regarding activity limitation, symptoms as well as emotional function domains. The highest percent of caregivers had low quality of life concerning activity limitation and emotional function domains. Conclusion: The findings of the present study concluded that bronchial asthma is affecting the quality of life for both children and their caregivers as the majority of children and their caregivers exhibited low quality of life. Recommendations: Conducting continuous training and health education sessions using simplified brochures and leaflets including domains of health promoting quality of life for both children with bronchial asthma and their caregivers.

Keywords: bronchial asthma, quality of life, children and their caregivers.

1. INTRODUCTION

Bronchial asthma (BA) is a major clinical concern around the world among children that impairing not only the quality of life of the children but also their families' caregivers (Ibrahim et al., 2019). It is a highly prevalent chronic condition affecting children. Globally, there is a large geographical variation in BA prevalence, severity, and mortality among children (Dharmage, Perret & Custovic, 2019). According to The Centers of Disease Control and Prevention (CDC), approximately 8.3% of children in the United States had BA. Boys were slightly more likely to have BA than girls at a rate of 9.2% and 7.4%, respectively (Centers for Disease Control and Prevention [CDC], 2021). In Egypt the prevalence of BA among school children estimated 7.6% in 2017 (Meatty, El-Desoky, El-Domyaty, El-Gilany & Nasef, 2018). Bronchial Asthma is a common pulmonary condition which defined as a chronic inflammatory disorder of the airways. It is characterized by bronchial inflammation, hyper-responsiveness and variable airflow obstruction, that is often reversible either spontaneously or with treatment. The fundamental problem in bronchial asthma appears to be immunological in which young children show signs of excessive inflammation of airways during the early stage of BA (Aggarwal et al., 2019).

According to (WHO), the Quality of Life (QoL) is defined as an individuals' 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 concerns (The Whoqol Group, 1998). It is a broad ranging concept that is affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment (Karimi & Brazier, 2016).

The assessment of children's QoL especially in those with chronic illness such as bronchial asthma is particularly important. It differs from other forms of assessment in which it focuses on the individual's own view of his well-being and other aspects of life so, it gives a more holistic view of well-being (Coban & Aydemir, 2014). Furthermore, the caregivers' QoL are also assessed to determine the caregivers' burden and the sorts of health care services. These are including not only for children, but also psychological or social assistance for caregivers due to children's illness. Caregivers' QoL assessment may also serve as a guide for family to enhance their well-being (Chow, Morrow, Cooper Robbins & Leask, 2013).

Bronchial Asthma might have physical, social, and emotional impact on children's lives. Children with bronchial asthma may be at higher risk of limited participation in their daily living activities, sleeping night disturbances, frequent school absenteeism, poor school performance, anxiety and depression (Roncada et al., 2016).

The primary caregiver may face a considerable burden with childhood bronchial asthma that affects his quality of life. Caregivers of children with BA are limited in their own normal daily activities and also experience anxieties due to their children's illness. Caregivers of asthmatic children appear to be more compromised in their resistance to stress, mood, emotional stability, and amount of spare time and leisure activities (Groen & Raat, 2012).

The pediatric nurse has a crucial role to improve the health of children with bronchial asthma and consequently enhance QoL for both children and their caregivers. It includes various responsibilities to promote physical, psychological and social condition. In addition to, the pediatric nurse should also teach children and their caregivers general principles of bronchial asthma care to maintain good quality of life (Mosenzadeh, Ahmadipour, Mardani, Ebrahimzadeh & Shahkarami, 2019).

Aim of the study

The aim of the study is to:

Determine quality of life among children with bronchial asthma and their families' caregivers.

Research Questions:

1. What is quality of life among children who are suffering from bronchial asthma?
2. What is quality of life among families' caregivers of children with bronchial asthma?

2. MATERIALS AND METHOD

Materials:

Research design:

A descriptive research design was used to accomplish this study.

Settings:

The study was conducted at pediatric outpatient, inpatient departments and pediatric allergy clinic at Damamhur Medical National Institute.

Subjects:

A convenient sample of 100 children with bronchial asthma and their caregivers from the previously mentioned settings who fulfilled the following criteria comprised the subjects:

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- Age is ranged from 7 to 12 years.
- Diagnosed with bronchial asthma since at least 6 months.
- Free from any other chronic diseases.

Tool one: Socio-demographic characteristics of children with bronchial asthma and their caregivers as well as children's clinical data structured interview schedule

This tool was developed by the researcher, it included two parts:

Part I: A: Socio-demographic characteristics of asthmatic children included age, gender, birth order and educational level.

B: Socio-demographic characteristics of caregivers involved age, gender education, occupation, income and residence.

Part II: Clinical data of children with bronchial asthma covered ,medical history age of onset of bronchial asthma, triggers of bronchial asthma attacks, clinical manifestations, bronchial asthma discovery methods, previous hospitalization and its frequency, family history, treatment during attack of bronchial asthma, preventive measures for the recurrent attack of asthma and follow up.

Tool two: Pediatric Asthma Quality of life Questionnaire with Standardized Activity (PAQLQS)

This tool was designed by Juniper, Buist, Cox, Ferrie and King (1999), revised in 2012 by Wing et al. (2012) and adopted . The PAQLQS was a disease-specific questionnaire for children with bronchial asthma. It was intended to assess QoL in children from 7 to 17 years old. It described how bothered and often have the child been during the last week because of asthma. It included 23 questions in three domains that involved activity limitation, symptoms and emotional function

Tool three: Pediatric Asthma Caregiver's Quality of Life Questionnaire (PACQLQ)

This tool was developed by Juniper et al. (1994), revised in 2012 by Stelmach et al. (2012) and adopted. This self-administered questionnaire assessed the quality of life of caregivers of children with bronchial asthma. It explored how often and worried have the caregiver been during the last week because of the child's asthma. It had 13 questions in two domains involved activity limitation and emotional function.

Method:

- An approval from the Research Ethics committee of the Faculty of Nursing, Alexandria University was obtained before carrying out this study.
- An official letter from the Faculty of Nursing, Alexandria University was directed to the responsible authorities of pediatric outpatient, inpatient departments and pediatric allergy clinic at Damanhur Medical National Institute to conduct the study after explaining its purpose.
- A written approval was obtained from hospital administrative personnel after explaining the aim of the study to collect the necessary data.
- Tool I was developed by the researcher after reviewing the recent and related literature.
- Validity for tool I was conducted by five experts in pediatric nursing field in the Faculty of Nursing, Alexandria University.
- Tool II and tool III were adopted and translated into Arabic language; its translation and validity were verified by five experts in the pediatric nursing field in the Faculty of Nursing, Alexandria University.
- Reliability of tool II and tool III was ascertained by measuring the internal consistency of their items using Cronbach's Coefficient Alpha test were ($r=0.937$)for children, ($r=0.900$) for their caregivers respectively.
- A pilot study was carried out by the researcher on 10 asthmatic children and their caregivers (10% of sample size) to test the feasibility and applicability of the tools. Those children and their caregivers were excluded from the total study subjects.

- Every caregiver and his child were interviewed individually in the waiting room of both the pediatric outpatient department and pediatric allergy clinic after receiving medication and physical examination. While, in cases of hospitalization, every caregiver and his child was interviewed individually in private room in pediatric inpatient department.
- The researcher collected socio-demographic characteristics of child, his caregiver as well as clinical data of the child using tool I.
- The researcher estimated QoL levels of the child and his caregiver using tools II and III.
- The time elapsed for every interview with child and his caregiver was approximately ranged from 30 to 40 minutes.
- Data was collected from the period of August to December, 2018.

Ethical considerations:

- A written informed consent from the study subjects was obtained after explanation of the study's aim.
- Anonymity and privacy of subjects was ensured.
- Confidentiality of the data was maintained.

3. RESULTS

Table (1) illustrates percentage distribution of socio-demographic characteristics of children with bronchial asthma. It shows that nearly three quarters of children (76 %) were males. About two thirds of children with BA (62%) aged from 7 years to less than 9 years old with a mean of age 8.01 ± 1.61 . It is evident that slightly less than half of asthmatic children (46 %) were in the second grade of primary school. Concerning birth order, the first born child constituted 61% of children, while only 5% of them were the fourth & more child in their families.

Percentage distribution of socio-demographic characteristics of caregivers of children with bronchial asthma is shown in **table 2**. It is cleared from this table that the majority of caregivers (87%) were mothers. Forty three percent of caregivers aged from 30 to less than 35 years old, on the other hand the age of only 6% of them were less than 25 years old with a mean of age 32.26 ± 4.2 . Regarding caregivers' educational level, 44% of caregivers finished their university educational level, while the minority of them (5 %) was illiterate. According to caregivers' occupation, 57% of them were not working. Forty two percent of caregivers lived in rural areas, while the rest of them (58%) lived in urban one. Moreover, the income of 59% of the caregivers was inadequate for their living.

Table (3) represents percentage distribution of levels of children's quality of life. It is clarified that the highest percent of children exhibited low quality of life level regarding activity limitation, symptoms as well as emotional function domains with a mean was 13.82 ± 5.02 , 24.80 ± 9.44 and 20.25 ± 7.16 respectively. Generally, approximately three quarters of children (76%) experienced low quality of life level in all domains with a mean was 58.87 ± 19.04 .

Table (4) portrays percentage distribution of levels of caregivers' quality of life. The highest percent of caregivers (79%) and (76%) respectively) had low quality of life concerning activity limitation and emotional function domains with a mean (10.56 ± 4.02 and 23.11 ± 9.61 respectively). Therefore, the majority of them (80%) exhibited low quality of life level in all domains with a mean was 33.67 ± 12.51 .

The relationship between children's quality of life levels and their caregivers' quality of life declares in **table 5**. The majority of children (89.5%) who had low quality of life levels their caregivers had also low quality of life levels. A statistical significant difference was found between children's quality of life levels and their caregivers' quality of life levels ($P= 0.000^*$).

4. DISCUSSION

Bronchial Asthma is one of the most frequently reported pediatric chronic disorders. It is ranking among the top 20 conditions for disability-adjusted life years in children (Qu & Zhang, 2017). Globally, death rates from BA in children ranged from 0 to 0.7 per 100,000 people in 2016. Bronchial asthma is considered the first cause of school absenteeism and the third one of hospitalization among children under 15 years of age (Serebrisky & Wiznia, 2019). The consequences of BA include many dimensions as physical, emotional, social and activity limitation that influence the quality of life. So,

BA might cause significant decrease in the standards of QoL for both children and their caregivers (Shaikhan & Makhlof, 2020).

Bronchial Asthma is a stressful condition for children that negatively affect different aspects of their QoL including activity limitation, symptoms and emotional function (El-Gendi et al., 2016; Jović, Petrović-Tepić & Knežević, 2018). The current study findings revealed that three quarters of children had low quality of life level in all domains (Table 3). It could be due to children's complaining of dyspnea with effort and inability to achieve any required tasks during asthma attack that affect their daily living activities. In addition, nocturnal awaking and having sleeping troubles at night because of coughing and wheezing may lead to frequent school absenteeism and poor school performance. These findings are in harmony with (Kouzegaran, Samimi, Ahanchian, Khoshkhui & Behmanesh, 2018) who reported that children with BA have significantly lower quality of life than the other communities of children. On the other hand, Banjari et al. (2018) and Furtado et al. (2019) found that children aged from 7-11 years experienced better quality of life with bronchial asthma which contradicted with the present study finding.

Activity limitation domain is a part of quality of life which is affected by bronchial asthma (Lam et al., 2016). The results of the current study indicated that the highest percent of children had low quality of life regarding activity limitation domain (Table 3). This finding could be explained by children's perception that exercise might worsen the asthma attack and increase bronchial constriction which leads to suffocation and death. So, they refused to be engaged in physical activities. Moreover, caregivers' fears impose the children to be at rest most of time because their fear from physical activities and playing with peers that may induce BA. This result is in the same line with Elnady et al. (2019) who reported that most of children suffering from bronchial asthma had low quality of life concerning activity limitation domain. On the contrary to the current findings, Li et al. (2013) concluded that more than half of children with BA had moderate QoL regarding activity limitation domain.

Bronchial Asthma usually causes many emotional disturbances among children and affects their emotional function domain in quality of life (Petsios et al., 2013; Tunde-Ayinmode, 2015). It was found in the current study that the highest percent of children had low quality of life in their emotional function domain (Table 3). It could be justified by children's feeling of stigmatization of chronic disease as bronchial asthma and shaming of using inhaler in front of their friends, teachers and relatives which lead to low self-esteem and social isolation. In addition to, lack of children adjustment to disease management and their feeling of powerlessness. These results are in agreement with Fontan, Duwe, Santos and Silva (2020) who concluded that quality of life was low regarding emotional function domain among children with bronchial asthma. In contrast, Ayuk, Oguonu, Ikefuna and Ibe (2013) found that the majority of children with BA had high QoL in their emotional function domain.

Quality of Life of caregivers is also influenced negatively by having children with BA (Nilsson, Ödling, Andersson, Bergström & Kull, 2018). The present study reflected that the majority of caregivers had low level in all QoL domains (Table 4). This finding could be due to caregivers may face considerable burden as a results of frequent hospital visits either for follow up or management of BA attack. Furthermore, caring for children with BA results in increased load of caregivers more than caring for other healthy siblings. Limitations in social life of caregivers due to children's chronic illness and frequent work absenteeism that indirectly increase financial burden on the family. This result is in agreement with (Trzcieniecka-Green, Bargiel-Matusiewicz, Wilczyńska & Omar, 2015) and Roncada et al. (2018) who showed that caregivers of asthmatic children had significantly low quality of life level compared with caregivers of healthy children. On the other hand, Fernandes, (2014) who concluded that approximately half of caregivers of children with BA had better QoL.

Activities of caregivers are disturbed by disease of their children as bronchial asthma which is cleared in activity limitation domain of their quality of life (Elshazly, El Mahalawy, Gabr, Abd El Naby & Elzoghby, 2015). The finding of the current study revealed that the majority of caregivers had low QoL considering activity limitation domain (Table 4). It could be due their important participation in daily treatment of children with BA. Moreover, frequent long time of transportation to the hospital for treatment or follow up of children may interfere with caregivers' activities. This result is in the same line with Guo, Gao, Guo, Wen and Zeng (2015) who detected that the majority of caregivers of asthmatic children had low QoL in activity limitation domain.

Children with bronchial asthma induce many worries and emotional disturbances for their caregivers (Mendes, Cairo & Sant'Anna, 2013). In the present study, the highest percent of caregivers exhibited quality of life regarding emotional function domain (Table 4). It may be due to caregivers were afraid of leaving their children alone since bronchial asthma attacks may occur suddenly and their children may not be prepared to deal with. In addition to, their lack of knowledge and worry about the disease prognosis. This result is correspondent with Ekim and Ocakci (2016) who found that caregivers of children with BA had low QoL according to emotional function domain. A study done by Crespo and Silva (2014) was also stated that caregivers of children with BA had many emotional impacts as worries and fears about the long-term effects of children's medications and feelings of helplessness. While, the results of the present study were incongruent with Cano et al. (2007) who mentioned that most of caregivers of children with BA had high QoL concerning emotional function domain.

Caregivers' QoL can be influenced by QoL of their children as a result of BA and its effects (Battula, Arunashekar & Nagarajan, 2020; Morillo-Vanegas et al., 2020). The study finding revealed that there was a statistical significant relationship between QoL levels of both children and their caregivers (Table 5). It may be attributed to the fact that bronchial asthma is stressful condition for both children and their caregivers which put burden and negative effect on their QoL. The finding of Halwani et al. (2016) was in the same line with the present study because there was positive correlation between QoL of children and their caregivers' QoL as clarified by both children and their caregivers had low QoL level. While, it contradicts with the result of Nair, Nair and Sundaram (2014) who found that there was no relation between quality of life for both children and their caregivers.

Disparities in BA have been observed across many studies (Fuseini & Newcomb, 2017; Shah & Newcomb, 2018). The current study showed that BA was higher among male children (Table 1). It could be due to that male gender is one of the risk factors for BA probably because of the higher prevalence of atopy in boys than in girls (Tse et al., 2016). This result is supported by another prospective study that carried out by Kulkarni and Kulkarni (2017) who revealed that the highest percent of children who were suffering from BA were male. While, Akinbami and Schoendorf (2002) found that female children were more prone than males to be affected with BA.

In the current study, it was illustrated that the majority of children with BA aged from 7 years to less than 9 years old (Table 1). This may be explained in a way that children at this age are more prone to BA as they are exposed greatly to allergic materials (Trivedi & Denton, 2019). This result is correspondent with Noushadali, Mohandas and Hussain (2018) who found that more than half of children aged between 7-9 years old is more prone to BA when compare to the other age groups. In contrast, Matsunaga et al. (2015) revealed that most of children aged 11-12 years old had bronchial asthma.

5. CONCLUSION

Based on the findings of the current study, it can be concluded that BA is affecting the quality of life for both children and their caregivers. The majority of children and their caregivers exhibited low quality of life and the minority of them had high quality of life. Meanwhile, small percent of them had moderate quality of life.

6. RECOMMENDATIONS

- Implementing counseling program should be conducted for children with BA and their caregivers to improve their awareness about the disease manifestations, complications and proper management approaches.
- Illustrated manual booklet involving updated guidelines about healthy quality of life should be disseminated for both children with BA and their caregivers.
- Conducting continuous training and health education sessions using simplified brochures and leaflets including domains of health promoting quality of life for both children with BA and their caregivers.
- A hot-line telephone should be accessible for caregivers and their children suffering from BA.
- Mass media should raise the society awareness regarding BA among children to improve QoL for both children and their caregivers.

Table 1: Percentage distribution of socio-demographic characteristics of children with bronchial asthma (No =100)

Children's socio-demographic characteristics	No	%
Gender:		
- Male	76	76.0
- Female	24	24.0
Age (years):		
- 7-	62	62.0
- 9-	24	24.0
- 11-12	14	14.0
Mean \pm SD 8.01 \pm 1.61		
Educational grade in primary school:		
- 1 st	21	21.0
- 2 nd	46	46.0
- 3 rd	11	11.0
- 4 th	8	8.0
- 5 th	4	4.0
- 6 th	10	10.0
Birth order:		
- First	61	61.0
- Second	20	20.0
- Third	14	14.0
- Fourth and more	5	5.0

Table (2): Percentage distribution of socio-demographic characteristics of caregivers of children with bronchial asthma (No =100)

Caregivers' socio-demographic characteristics	No	%
Caregiver:		
- Mother	87	87.0
- Father	10	10.0
- Relatives	3	3.0
Age (years):		
- < 25	6	6.0
- 25 < 30	33	33.0
- 30 < 35	43	43.0
- 35 < 40	10	10.0
- 40 and more	8	8.0
Mean \pm SD 32.26 \pm 4.2		
Educational level:		
- Illiterate	5	5.0
- Basic education	11	11.0
- Secondary education	40	40.0
- University education	44	44.0
Occupation:		
- Not working	57	57.0
- Working	43	43.0
Place of residence:		
- Rural	42	42.0
- Urban	58	58.0
Family income:		
- Inadequate	59	59.0
- Adequate	41	41.0

Table 3: Percentage distribution of levels of children's quality of life (No 100)

Types of QOL domains	Children's QOL levels					
	Low		Moderate		High	
	No	%	No	%	No	%
• Activity limitation	61	61.0	35	35.0	4	4.0
Min- Max	5-28					
M ± SD	13.82 ± 5.02					
• Symptoms	78	78.0	20	20.0	2	2.0
Min- Max	10-58					
M ± SD	24.80 ± 9.44					
• Emotional function	73	73.0	26	26.0	1	1.0
Min- Max ⁹	8-45					
M ± SD	20.25 ± 7.16					
• Total children's QOL	76	76.0	23	23.0	1	1.0
Min- Max	28-131					
M ± SD	58.87 ± 19.04					

Table 4: Percentage distribution of levels of caregivers' quality of life (No 100)

Types of QOL domains	Caregivers' QOL levels					
	Low		Moderate		High	
	No	%	No	%	No	%
• Activity limitation	79	79.0	19	19.0	2	2.0
Min- Max	4-27					
M ± SD	10.56 ± 4.02					
• Emotional function	76	76.0	19	19.0	5	5.0
Min- Max	10-63					
M ± SD	23.11 ± 9.61					
• Total caregivers' QOL	80	80.0	15	15.0	5	5.0
Min- Max	19-83					
M ± SD	33.67 ± 12.51					

Table 5: Relation between the children's QOL levels and their caregivers' QOL levels

Children's QOL levels	Caregivers' QOL levels						Total N=100	X ²	P	
	Low (N=80)		Moderate (N=15)		High (N=5)					
	No	%	No	%	No	%				
- Low	68	89.5	8	10.5	0	0.0	76	76.0	37.61	0.000*
- Moderate	12	52.2	7	30.4	4	17.4	23	23.0		
- High	0	0.0	0	0.0	1	100.0	1	1.0		

X² = Chi square test * significant at < 0.

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