

## Asthma-Related Knowledge, Management and Burden among Mothers of Intellectually Disabled Children with Bronchial Asthma

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### Abstract

**Background:** Children with intellectual disability are at an increased risk of bronchial asthma. Unfortunately, no specific guidelines exist for dealing with and managing Intellectually Disabled (ID) children with Bronchial Asthma (BA). Recent innovations in medical care have shifted asthma treatment from hospitalization to ambulatory care. Consequently, mothers' care has become the most important part of the treatment, and almost all treatment responsibilities have fallen on them. **Aim:** to determine asthma-related knowledge, management, and burden among mothers of intellectually disabled children with bronchial asthma. **Design:** An explanatory sequential mixed design was used. **Settings:** All governmental intellectual disability schools distributed in 6 educational directorates affiliated with El-Beheira Governorate (6 mixed gender schools). **Subjects:** Purposive sample of mothers with children with intellectual disability and bronchial asthma. **Tools:** Four data collection tools were used to collect qualitative and quantitative data for the study; *For quantitative data*, three structured interview schedule tools were used as follows: *Tool I:* Personal Characteristics and Health Profile of Children, *Tool II and III:* Asthma-Related Knowledge and Management of Mothers Regarding their Intellectually Disabled Children with Bronchial Asthma. While for qualitative data, Tool IV Focus Group Discussion Guide (FGD) for the mothers of Intellectually Disabled Children with Bronchial Asthma was used. **Results:** It was found that the majority (78.6%) of mothers with a good BA knowledge level had a good BA management score. On the other hand, the majority (97.7%) of mothers with poor BA knowledge had a poor BA management score ( $X^2: 51.3, p < 0.001$ ). Regarding the qualitative data, it was clustered into four categorical schemes: 1: Caring role, 2: Constant concern, 3: Caring impacts on life and 4: Unmet needs. **Conclusion:** it can be concluded that more than half of the mothers of intellectually disabled children with bronchial asthma had a poor knowledge score. Moreover, more than two-thirds of them had a poor management score. Caring for intellectually disabled children with bronchial asthma negatively affects mothers' health, relationships, social status, financial stability, emotional and psychological well-being. The mothers struggle with unmet social, psychological, and financial needs. **Recommendations:** The current study recommended raising awareness, designing an asthma management training program and providing psychological and social support for mothers of intellectually disabled children with bronchial asthma to improve the care provided to their children.

**Keywords:** Bronchial Asthma, Intellectual Disability Children, Intellectual Education Schools, Mothers Burden, Knowledge, Management & Nursing

### Introduction

Bronchial asthma (BA) is one of the most common chronic diseases in children and adolescents around the world (Xie et al., 2020). It is characterized by a chronic inflammatory disease of the respiratory system that can cause an intermittent decrease in airflow to and from the lungs, resulting in dyspnea, chest tightness, wheezing, and coughing; BA may also spontaneously remit or improve with treatment. Bronchial asthma is the sixteenth leading cause of Years Lived with Disability (YLD), as well as the twenty-third leading cause of premature death (Elnady et al., 2019; Rethemiotakia, 2021). The global prevalence of BA in children ranges from 9.1% to 9.5%, rising to 10.4% in adolescents (Rahimian et al., 2021).

Children with Intellectual Disability (ID) are more likely to have BA than their normally developing peers, but the reason for this is unknown (Davis, 2016; Patrick et al., 2021). Intellectual disabilities are lifelong conditions that emerge during the developmental years and fall under the umbrella of developmental disabilities (DD), and range in severity from mild to severe (McKenzie et al., 2016; Patel et al., 2018). It is characterized by significant limitations in both intellectual functioning and adaptive behavior that begin before the age of 18. According to most recent meta-analysis findings, the prevalence of ID ranges from 0.05 – 1.55% globally among children and adolescents (McKenzie et al., 2016; Oliveira et al., 2020). Unfortunately, no studies have been conducted to estimate the prevalence of children

and adolescents with ID and BA. However, in a cross-sectional study of 71811 children aged 0–18 years, asthma prevalence estimates are approximately 16% in children with DD versus 6% in children without DD (Xie et al., 2020).

All international guidelines indicate that the primary aim of clinical asthma management is to achieve good asthma control which includes minimizing asthma symptoms, activity limitations, airway narrowing and rescue bronchodilator use. Asthma control is ranged from totally controlled to extremely poorly controlled, which is a life-threatening state (Juniper et al., 2010; Barik & Paul, 2018). Successful management of asthma actually needs awareness of asthma triggers and treatments such as corticosteroids use, proper inhaler technique, understanding an asthma action plan, understanding the use of a peak flow meter, accurate interpretation of breathing symptoms, and adherence to therapy (Barik & Paul, 2018; Erickson et al., 2018).

Unfortunately, no specific guidelines exist for dealing with and managing ID children with BA, and recent innovations in medical care have shifted asthma treatment from hospitalization to ambulatory care (Davis, 2016; Ekim & Ocakci, 2016). Moreover, when managing asthma in children with ID, certain factors must be considered. First, children with ID may have difficulty communicating their health needs to healthcare providers. As a result, mild and moderate respiratory problems may go unnoticed. Second, due to their cognitive, physical, and often sensory impairments, children with ID often need support with asthma self-management and assistance with taking medications such as inhalers. Third, the high level of medication use in people with ID, as well as its negative influence on medication adherence. Finally, children with ID experience health disparities as a result of gaps in access and quality of healthcare provision (Koehler et al., 2014; Guo et al., 2015; Davis, 2016; Erickson et al., 2018).

Consequently, mothers' care has become the most important part of the treatment, and almost all treatment responsibilities have fallen to the mother (Ekim & Ocakci, 2016; Erickson et al., 2018). Therefore, the mother should collaborate with the physician to develop a written asthma action plan (WAAP) based on the child's clinical characteristics and controller treatments. It should include information about the proper action for each level of exacerbation, as well as the doses and frequency of maintenance and rescue medications in response to specific signs and symptoms (Kouri et al., 2017; Pegoraro et al., 2022). Moreover, the

mother must be able to deal with medication problems that are unique to the needs of an asthmatic child with ID (Ekim & Ocakci, 2016; Erickson et al., 2018). In addition, the mother must be able to cope with other significant challenges, such as the significant financial burden imposed by long-term routine treatment, the care of other children, and the frequency of admissions to emergency services. Accordingly, the mother's personal and professional lives were negatively affected and will suffer from a relatively heavy burden (Guo et al., 2015; Ekim & Ocakci, 2016; Pars et al., 2020).

The concept of "mother's burden" refers to a high level of physical, psychological, emotional, behavioral and financial burden experienced by mothers who are caring for their children (Ekim & Ocakci, 2016). A study carried out by Koehler et al. (2014) reported that ID children with BA, who have a high mother's burden, have poorer adherence to asthma medications and are more likely to be hospitalized. Furthermore, several authors claim that mothers of ID children with BA have significantly higher rates of depression and workload, relatively low confidence, and poor asthma-related quality of life as a result of the additional stress of raising a child with two chronic illnesses.

The nurses play an important role in assisting mothers who have an ID child with asthma in coping with the difficulties and challenges they face, as well as supporting and empowering the ID child with BA to self-manage and reduce the risk of developing further health complications (El Sherbini et al., 2016; EL-Fahar et al., 2021). Little is known about the overall asthma control of an ID child with BA or the mother's ability to provide appropriate care for them.

### **Aim of the Study**

To determine asthma-related knowledge, management and burden among mothers of intellectually disabled children with bronchial asthma

### **Research Questions**

- 1- What is the level of mothers' asthma-related knowledge regarding their intellectually disabled children with bronchial asthma?
- 2- What is the level of mothers' asthma-related management regarding their intellectually disabled children with bronchial asthma?
- 3- What is the burden facing mothers of intellectually disabled children with bronchial asthma?

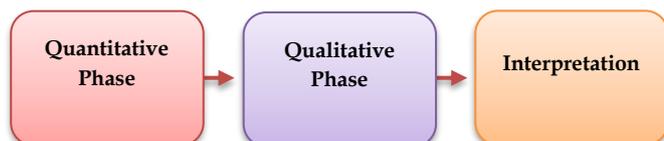
## Materials and Methods

### Materials:

### Design:

#### An Explanatory Sequential Mixed Design

An explanatory sequential mixed design emphasizes the quantitative data collection and analysis, and then the researchers conduct the focus group discussions (qualitative measures) to help explaining the quantitative results (Phenomenological explanatory sequential design).



**Figure 1: Explanatory Sequential Mixed Design (Toyon, 2021)**

### Setting:

The study was conducted in all governmental intellectual disability schools distributed in 6 educational directorates affiliated to El-Beheira Governorate (6 mixed gender schools) *Table (1)*.

### Subjects:

Purposive sample of mothers of intellectual disabled children with bronchial asthma and registered in previous mentioned schools *Table (1)*. The studied mothers are selected based on the following inclusion criteria:

### Inclusion criteria of the study subject:

- Mothers of children having IQ test score not below 50%
- Mothers of children diagnosed with bronchial asthma for more than 6 months.
- Willing to participate in the study.

### Sample Size for Quantitative Data:

- El-Beheira Governorate includes eighteen educational directorates, only six educational directorates having intellectual education schools as follows: Bander Damanhour, Itay El Barud, Bander Kafr El Dawwar, Shubrakhit, Mahmoudiyah and Kom Hamada. Each of these educational directorates has only one governmental intellectual education school (mixed gender, primary, preparatory and vocational educational level).
- The total number of students who attend 6 selected schools was 1239. Only 75 mothers fulfilled the previous inclusion criteria of the study. They were selected by using the purposive sampling technique. *Table (1)*

### Sample Size for Qualitative Data:

The three Focus Group Discussions (FGDs) were conducted in the above-selected settings for the study subject. Subjects were enrolled for each focus group randomly and composed of 5-7 mothers. The total number of mothers included in this study was 19 mothers.

**Table 1: Sample Size Estimation Table**

Educational Directorates	Intellectual Education School Name (Mixed gender schools)	Total Schools' Students	Total Sample Size (Mothers who Fulfil the inclusion criteria)
1. Bander Damanhour	Naser Intellectual Education School	317	13
2. Itay El Barud	Itay El Barud Intellectual Education School	198	5
3. Bander Kafr El Dawwar	Kafr El Dawwar Intellectual Education School	318	4
4. Shubrakhit	Shubrakhit Intellectual Education School	164	16
5. Mahmoudiyah	Mahmoudiyah Intellectual Education School	102	9
6. Kom Hamada	Kom Hamada Intellectual Education School	140	28
<b>Total</b>		<b>1239</b>	<b>75</b>

### Data Collection Tools:

Four tools were used to collect the required data for the study.

#### Quantitative Data Collection Tools:

**Tool I: Personal Characteristics and Health Profile of Intellectually Disabled Children with**

### Bronchial Asthma Structured Interview Schedule:

This tool was developed by the researchers after reviewing the relevant literature (Davis, 2016; American Academy of Pediatrics [AAP], 2022). It is comprised of two parts and was answered by the mothers in the relevant school setting:

- **Part (1): Personal Characteristics of ID children with BA:** it included items related to age (year), gender, educational level, birth order, number of siblings and registered Intelligence Quotient (IQ) in their school records.
- **Part (2): Health Profile of ID children with BA:** it comprised items such as the family history of BA, duration of BA, triggers of BA attacks, most common reasons that trigger BA, most common asthma symptoms, previous hospitalization and its frequency, medications used during attack of BA, can use inhaler independently, preventive measures for the recurrent attack of BA, adherence to following up, availability of having rehabilitation services for children and their BMI.

#### **Tool II: Mothers' Asthma-Related Knowledge Structured Interview Schedule:**

This tool was developed by the researchers after reviewing the recent literature (**Centers for Disease Control and Prevention (CDC), 2021b; American Academy of Pediatrics, 2022; Lizzo & Cortes, 2022**) to measure mothers' personal characteristics, bronchial asthma knowledge regarding their ID children with BA, and their source of information. It comprised the following parts:

- **Part (1): Personal characteristics of mothers:** it involved items such as age (year), marital status, educational level, occupation, type of family and monthly income.
- **Part (2): Bronchial Asthma-Related Knowledge:** It includes 11 sections composed of 30 questions. These sections are (1) the definition of asthma, (2) how the lungs work, (3) how asthma affects the lungs, (4) symptoms, (5) precipitating asthma triggers whether indoors or outdoors, (6) risk factors, (7) diagnosis, (8) asthma medication [e.g., action, types (e.g., fast-acting and slow-acting), devices for inhaled medications], (9) potential side effects, (10) danger signs, and finally (11) BA complications.

#### **Total Knowledge score:**

The response to each question was scored as (2) for correct and complete answers, (1) for correct and incomplete answers and (0) for incorrect and don't know ones. Total knowledge score ranged from 0 to 60. The total number was summed up for each subject and was divided by 30 to get the percent of knowledge level. If the total score is less than 50%, the knowledge is poor, from 50-65% the knowledge is fair; and if the total score is >65%, it means that the knowledge is good.

- **Part (3): Mothers' Sources of BA information:** The mothers were asked about the sources of their BA information such as family members, friends, neighbors, or physicians, and nurses.

#### **Tool III: Mothers' Asthma-Related Management Structured Interview Schedule:**

This tool was developed by the researchers after reviewing recent literature (**Centers for Disease Control and Prevention (CDC), 2018, 2022a, 2022b, 2022c**) to measure how mothers can prevent and control asthma attacks of their children in different conditions.

#### **This tool depends on the following steps:**

- **Step 1: Asthma Action Plan (AAP):** The mother was asked to answer the following 8 questions: 1) does your child have a cough, wheezing, chest tightness, or trouble breathing at any time?, 2) can your child do all things he/she usually does?, 3) does your child have a peak flow of more than 80 percent or more?, 4) is your child still taking her/his long-term control medicine?, 5) does your child take her/his quick-relief medicine?, 6) does your child wake up at night because of her/his asthma?, 7) does your child go to the hospital when her/his symptoms do not get better?, 8) does your child regularly maintain follow-up?
- **Step (2): Childhood Asthma Control:** it includes 6 questions to measure the full range of the child's clinical impairment as reported by the mothers from "totally controlled= in which the child has no impairments or limitations to extremely poorly controlled= which is a life-threatening state". These questions include the following top 5 symptoms such as "woken at night by symptoms, wake in the mornings with symptoms, limitation of daily activities, shortness of breath and wheezes" and "one" question about rescue bronchodilator use. The mother was asked to recall how her child's BA has been during the previous week.

#### **Total Asthma Management Score:**

- **Step 1; Asthma Action Plan Score:** The mother was invited to respond to 8 questions on a 3-point Likert scale (*Always, sometimes, and never*). For each question, if the answer to questions (2,3,4,5,7 and 8) is "always" take 2 points, while if the answer to questions (1 and 6) is "never" take 2 points. If the answer is "sometimes", it takes 1 point, and if the answer is "never", it takes 0 points. Questions 1 and 6 take reversed scores. **Total Asthma Action Plan Score** was ranged from 0 to 16 points, If the total score is less than 50%, it means that the child in Red Zone (medical alert), and from

50-65% means that the child in Yellow Zone (asthma is getting worse). Finally, if the total score >65%, it means that the child in Green Zone (doing well).

- **Step 2: Childhood Asthma Control Score:** The mother was invited to respond to 6 questions on a 7-point Likert scale (0 = no impairment to 6 = total impairment). For each question, if the answer is “never”, it takes 2 points. If the answer is “sometimes”, it takes 1 point and if the answer is “always”, it takes 0 points. **Total Childhood Asthma Control Score** ranges from 0 to 12. If the total score is less than 50.0%, it means that the asthma is uncontrolled and from 50-65% means that the asthma is partially controlled. Finally, if the total score >65%, it means that the asthma is controlled.

**Total asthma management score** ranged from 0 to 66 points and was divided by the maximum to get the percent of total asthma management scores. If the total score is less than 50.0%, it means that the asthma management was Poor. If the total score ranges from 50-65%, the asthma management was *Fair* and finally if the total score is >65%, it means that the asthma management was *Good*.

#### Qualitative Data Collection Tool:

#### **Tool IV: Focus Group Discussion Guide (FGD) for the Mothers of Intellectually Disabled Children with Bronchial Asthma:**

It was developed by the researchers after a thorough review of literature (Koehler et al., 2014; Davis, 2016; Klagge, 2018) to collect qualitative data from the mothers of the intellectually disabled children with bronchial asthma. The researcher performed face-to-face, semi-structured interviews with the use of an interview guide that had numerous open-ended questions to encourage the study mothers' free, in-depth, and reflective descriptions regarding experienced burden imposed by caring for their intellectually disabled children with bronchial asthma.

#### Method:

- An **official letter** from the Faculty of Nursing, Damanhour University was directed to the Education Directorate in El-Beheira Governorate to have their approval to conduct the study.
- Meetings were conducted with **directors of the six intellectual education schools** to clarify the purpose of the study and to gain their cooperation during data collection.
- **Tools I, II, III and IV were developed** by the researchers after a thorough review of the literature and translated into Arabic.

- Tools II and III were tested and revised by 5 experts in the related fields of community health nursing and pediatric nursing for **content validity**. Necessary modifications were done accordingly.
- The **reliability** of tools II and III were emphasized using Cronbach's Alpha Coefficient, which was 0.97%, and 0.93% respectively.
- A **pilot** study was carried out on a selected sample of 8 mothers, who are excluded from the main study's subjects, to test the feasibility and the applicability of the *quantitative tools*.
- Focus group study **pilot** was done by the researchers on 2 mothers to ascertain the relevance, test wording of the questions, estimate the time required for the focus group discussion, clarity, and applicability of the *qualitative tool*. The necessary modifications were done.

#### Quantitative data collection:

- The mothers were **interviewed individually** by the first researcher using the study tools (I, II, and III) and lasted from 35 to 45 minutes.
- The second researcher **measured the height** of ID children with BA during mothers' attendance to feel secure and gain cooperation from the children. The height was measured to the nearest 0.5 cm and the **weight** to the nearest 0.1 kg using an electronic scale. The body mass index (BMI) was calculated based on the Center for Disease Control and Prevention BMI charts. BMI was interpreted based on the norm for age and sex, to be an underweight, healthy weight, overweight, or obese (**Centers for Disease Control and Prevention (CDC), 2021a**).
- **Data was collected** in the accessible classroom in the schools, during the academic year (2021-2022) over a period of 2 months (starting from beginning of the October 2021 to the end of November 2021).

#### Qualitative data collection:

- The FGD sessions were held in a classroom in the selected settings, it was conducted twice weekly and ranged from 50 to 60 minutes in duration through using (**Tool IV**).
- The FGD sessions were organized and implemented as follows.
  - **Introduction: (ice-breaking questions):** these questions were used to help mothers ease into the discussion and to express their opinions freely regarding the care of their intellectually disabled children with bronchial asthma and its burden.

- **Exploration questions (Key questions):** these questions were used through verbal and nonverbal communication such as head shaking and asking open-ended questions in accordance with the FGDs guide. They included open-ended questions about what they know about asthma, how it affects their lives, which difficulties they have had, what they have done during such difficulties, what they have experienced in this process, and which coping mechanisms they have used.
- **Engagement questions:** the researcher actively encouraged the participation of everyone in the group and emphasized the importance of every participant's input and opinion through asking questions such as "could you please provide more information about this subject" or "could you please give more details". Diversity of comments and opinions among the group was encouraged and flexibility for clarification and probing was allowed. Engagement questions were aimed to comprehensively examine the following themes: Theme 1: Caring role, Theme 2: Constant concern, Theme 3: Caring impacts on life and Theme 4: Unmet needs.
- **Exit question (closing question)** such as: is there anything else they would like to say?
- **Data verification:** to improve the trustworthiness of the data, a detailed diary was completed by the moderator after each set of focus groups, to serve as an audit trail.
- **Data recording:** All transcripts of FGDs were audio recorded and the researchers took notes during the discussion.
- **Qualitative data was collected** over a period of 1 month (starting from the beginning of December 2021 to the end of December 2021).

#### Ethical considerations:

- Ethical approval to conduct the current study was obtained from the ethical committee of the Nursing Faculty, at Damanhour University.
- Written consent from the directors of each school was obtained to conduct the study.
- Written approval from the studied mothers was obtained after an appropriate explanation of the purpose of the study.
- Participation was totally voluntary, and no incentives were provided to the participants.
- Participants' privacy and confidentiality of the collected data were maintained.

#### Statistical analysis:

##### Quantitative data analysis:

The Data was collected and entered into the computer. Statistical analysis was done using IBM SPSS software package version 24.0. Mean and standard deviation was calculated for numerical data. The number and percent for each category were calculated, and for categorized parameters, the chi-square ( $\chi^2$ ) test was used. The level of significance was 0.05. Multivariable linear regression was used to determine which mothers' and children's characteristics and children's health profiles influence poor knowledge scores and poor management scores.

##### Qualitative data Analysis:

- After the completion of all sessions, the data was organized for analysis by collecting all transcripts from the tapes. Each focus group session was transcribed verbatim (word for word) to capture the exact words and phrases voiced by the mothers that captured their perspectives and experiences.
- Proofread (read through for errors) to check the accuracy of all transcripts against the audiotape were done. Findings together with pertinent quotations were then organized according to the discussed topics.
- The main categories covering the objectives behind the research were formulated. Examination of each category was carried out to search for subtopics and to select the most useful for various ideas, followed by clustering the categories into themes. These themes provide the major heading for the results.

#### Result

##### Part (1): Results of Quantitative Data:

This study was carried out on 75 intellectually disabled children with bronchial asthma and their mothers, the different data was collected, analyzed, and tabulated.

*Table (2)* shows the distribution of the ID Children with BA and their mothers according to personal characteristics. **In relation to personal characteristics of ID children with BA.** Regarding age, it ranged from 6-15 years with a mean age of  $10.52 \pm 2.91$ . Girls were (n:33, 44%) and boys were (n:42, 56%). Primary education grade was observed among (n:48, 64%) of the children followed by preparatory grade (n:23, 30.7%). Concerning birth order, more than one-third (n: 29, 38.7%) of children were the third or more followed by second (n: 28, 37.3%). Yet, 56% of them had two siblings followed by one sibling among 30.7% of them.

**Regarding mothers' characteristics**, the table shows that less than half (48.0%) of them were aged more than 35 to less than 40 years. However, mothers' ages ranged from 22 to 48, with a mean age of 34.79  $\pm$  5.23. Most of the mothers were married ( $n = 64$ , 85.3%). Less than half ( $n = 33$ , 44%) of them had secondary education, while 56% of mothers were housewives. It was noted that less than two-thirds (60%) of them lived in nuclear families. Moreover, less than two-thirds (61.3%) of them did not have enough money.

**Table (3)** shows the percentage distribution of ID Children with BA according to their health profile. It is clarified that more than one-third (36%) of children have a family history of bronchial asthma. In terms of BA duration, less than half (46.6%) have had it for 6 years or more. The most trigger factors of asthma attacks were weather change, and respiratory infections (92%, and 77.3% respectively). Winter was the most season that triggers BA attacks in the majority of children (94.7%). The most common symptoms of BA presented by children were cough, wheezing, and difficulty breathing (92%, 77.3%, and 56% respectively). Less than one-half (41.3%) of children were previously hospitalized and 54.7% of them were hospitalized only once. Bronchodilators and corticosteroids were the most frequent (84%) treatments used during an attack of BA, while 57.3% of the children couldn't use the inhaler independently.

Concerning preventive measures of mothers for recurrent asthma attacks, the table shows that avoidance of trigger factors and medication compliance (73.4, and 57.3% respectively) were the most common preventive measures that were followed by mothers for the recurrent attack of BA. It was found that 72.0% of the children had regular follow up. While 54.7 of them have rehabilitation services. The majority of the children (46.7% and 44.0%) had healthy weights or were overweight, respectively.

**Table (4)** shows the distribution of the studied mothers according to their sources of BA information. The most frequent source of information was the physician (96.0%), followed by social networks and websites (69.3%), and finally the nurses (66.7%).

**Table (5)** shows the distribution of the studied mothers according to their BA knowledge total score. It was found that more than half (58.6%) of mothers had poor knowledge, while only 18.6% of them had a good knowledge level with a mean of 31.2 $\pm$ 10.1.

**Table (6):** Regarding the total BA management score, it was found that 66.7% of mothers had a poor management score, 17.3% had

a fair management score, and 16.0% had a good management score with a mean of 5.82 $\pm$ 2.83.

**Table (7)** shows the relation between mothers' total BA knowledge score and their total BA management score. It was found that the majority (78.6%) of mothers with a good BA knowledge level had a good BA management score. On the other hand, the majority (97.7%) of mothers with poor BA knowledge had a poor BA management score ( $X^2$ : 51.3,  $p < 0.001$ ).

**Table (8)** shows the multivariate analysis of different potential risk factors for poor knowledge about mothers of BA children. There was a significant relation between the age of children and the level of mothers' knowledge. It was found that the mothers of children younger than 12 years were 2.11 times more likely to have poor knowledge. The most important risk factor affecting poor asthma knowledge was the mother's education. The illiterate/read-and-write mothers had poor knowledge levels by 14.82 times more than the university or high-level mothers. The basic education level significantly increased the poor knowledge by 8.36. The poor level of knowledge among housewives increased by 3.27 more than working women ( $p < 0.001$ ). Monthly income had a significant effect on asthma knowledge level; poor knowledge increased by 3.62 times in mothers with insufficient income more than sufficient one. Whereas the family history of BA had no significant effect on the level of knowledge.

The duration of BA increased the level of knowledge about it, the mothers of children with short BA duration (6 months) had a poor level of knowledge by 4.73 times more than the duration of 6 years and more. The poor level of knowledge increased significantly in mothers of BA children with no previous hospitalization by 1.98 times. Meanwhile, the poor knowledge level increased by 3.36 times for only one hospitalization time. Finally, the poor knowledge level increased by 2.81 times in the case of a lack of rehabilitation services.

**Table (9)** shows the multivariate analysis of different potential risk factors for poor management of mothers of BA children. There was a significant relation between the age of children and the level of mothers' management. It was found that the mothers of children younger than 12 years were 2.98 times more likely to have poor management ( $p < 0.001$ ). There was a significant relation between the level of asthma management and birth order, poor asthma management increased by 2.54 times in the first-born child more than the second or third child.

The most important risk factor affecting poor asthma management was the mother's education. the poor management increased by 10.21

times in illiterate/read and write mothers more than the university or high-level mothers. the poor management increased significantly by 3.14 in the basic education level. The mother's occupation shows no significant effects on the level of asthma management. On the other hand, monthly income had a significant effect on asthma management level; poor management increased by 2.76 times in mothers with insufficient income more than sufficient one. The family history of BA has a significant effect on the level of asthma management; the poor management increased significantly by 3.14 in the case of no family history more than the presence of a family history.

The duration of BA increased the level of management about it, the mothers of children with short BA duration (6 months) had a poor level of management by 4.25 times more than the duration of 6 years and more. The poor level of management increased significantly in mothers of BA children with no previous hospitalization by 2.89 times. Meanwhile, the poor management level increased by 3.51 times in one hospitalization time. Finally, the poor management level increased by 2.94 times in the case of a lack of rehabilitation services.

**Part (1): Results of Quantitative Data:****Table (2): Distribution of the ID Children with BA and their mothers according to Personal Characteristics**

Variables	(n= 75)	
	No	%
<b>Personal Characteristics of the ID Children with BA</b>		
<b>Age (year)</b>		
• 6-	43	57.3
• 12-	32	42.7
Min – Max.	6 – 15	
Mean + SD.	10.52±2.91	
<b>Gender</b>		
• Girl	33	44
• Boy	42	56
<b>Educational Level</b>		
• Primary	48	64.0
• Preparatory	23	30.7
• Vocational	4	5.3
<b>Birth order</b>		
• First	18	24.0
• Second	28	37.3
• Third or more	29	38.7
<b>Siblings number</b>		
• One	23	30.7
• Two	42	56.0
• Three or more	10	13.3
<b>Personal Characteristics of the mothers of ID Children with BA</b>		
<b>Age (year)</b>		
• <25	1	1.3
• 25 -	11	14.7
• 30 -	20	26.7
• 35-	36	48.0
• 40 and more	7	9.3
Min.-Max.	22-48	
Mean + SD	34.79±5.23	
<b>Marital Status</b>		
• Married	64	85.3
• Divorced/widow	11	14.7
<b>Educational Level</b>		
• Illiterate/read & write	4	5.3
• Basic education (Primary, preparatory)	8	10.7
• Secondary	33	44.0
• University or higher	30	40.0
<b>Occupation</b>		
• Housewife	42	56
• Working	33	44
<b>Type of family</b>		
• Nuclear	45	60
• Extended	30	40
<b>Monthly Income</b>		
• Not enough	46	61.3
• Enough	29	38.6

Table (3): Distribution of the ID Children with BA according to their Health Profile

Clinical feature	ID children with BA (n= 75)	
	No	%
<b>Family History of BA</b>		
• Yes	27	36
• No	48	64
<b>Duration of BA</b>		
• 6 months -	10	13.3
• 1 year -	14	18.7
• 3 years -	16	21.3
• 6 years and more	35	46.6
<b>Triggers of BA Attacks *</b>		
• Weather change	69	92.0
• Respiratory infections	58	77.3
• Smoking	42	56.0
• Fumes, house dust and air pollution	40	53.3
• Physical activity	31	41.3
• Some foods	6	8.0
• Pets and pollen	5	6.7
• Blankets, sheets and toys stuffed with fiber	2	2.7
• Household insects and cockroaches	2	2.7
<b>Most common seasons that trigger BA: *</b>		
• Winter	71	94.7
• Spring	11	14.7
• Autumn	52	69.3
• Summer	3	4
<b>Most common BA Symptoms: *</b>		
• Cough	69	92.0
• Wheezing	58	77.3
• Difficulty breathing	42	56.0
• Tachypnea	8	10.7
• Chest tightness	10	13.3
<b>Previous Hospitalization</b>		
• Yes	31	41.3
• No	44	58.7
<b>Frequency of Hospitalizations</b>		
• Once	17	54.7
• Twice	10	32.2
• Three times more	4	12.9
<b>Treatment during Attack of BA</b>		
• Bronchodilators& Corticosteroids	63	84
• Bronchodilators	10	13.3
• Corticosteroids	2	2.7
<b>Can use inhaler independently</b>		
• Yes	32	42.7
• No	43	57.3
<b>Preventive measures for the recurrent attack of BA *</b>		
• Avoid triggering factors	55	73.4
• Medications compliance	43	57.3
• Regular follow up	25	33.3
<b>Adherence to Follow up</b>		
• Yes	54	72
• No	21	28
<b>Have Rehabilitation Services</b>		
• No	34	45.3
• Yes	41	54.7
<b>BMI</b>		
• Underweight	4	5.3
• Healthy Weight	35	46.7
• Overweight	33	44.0
• Obese	3	4.0

\* More than one answer

**Table (4): Distribution of the studied Mothers according to their sources of BA information.**

Sources of BA Information *	(N=75)	
	No.	%
• Family Members	46	61.3
• Friends or Neighbors	26	34.7
• Media (Television and Radio)	35	46.7
• Physician	72	96.0
• Nurse	50	66.7
• Social Networks/Websites	52	69.3

\* Multiple answers.

**Table (5): Distribution of the studied Mothers according to their BA knowledge total score.**

Items	Poor Knowledge (<50%)		Fair Knowledge (50%-65%)		Good Knowledge (≥65%)	
	No.	%	No.	%	No.	%
<b>Levels of Mothers' Knowledge (0- 60)</b>	44	58.6	17	22.6	14	18.6
▪ Min - Max	13-45					
▪ Mean ± SD	31.2±10.1					
▪ Mean Percent Score	52.0%					

**Table (6): Distribution of the studied Mothers according to their BA management total score.**

Items	Poor Management (<50%)		Fair Management (50%-65%)		Good Management (≥65%)	
	No.	%	No.	%	No.	%
<b>Levels of Mothers' BA management (0-66)</b>	50	66.7	13	17.3	12	16.0
▪ Min - Max	2-10					
▪ Mean ± SD	29.8±21.8					
▪ Mean Percent Score	44.7%					

**Table (7): Relation between mothers' total BA knowledge score and their total BA management score.**

Total BA Management score	Total BA knowledge score						Total
	Poor "n=44"		Fair "n=17"		Good "n=14"		
	No.	%	No.	%	No.	%	
Poor	43	97.7	7	41.2	0	0.0	50
Fair	1	2.3	9	52.9	3	21.4	13
Good	0	0.0	1	5.9	11	78.6	12
X <sup>2</sup>	51.3						
P value	0.001*						

X<sup>2</sup>= chi square test , \*P significant if < 0.05 , P was calculated by chi square test

Table (8): Multivariant analysis of different Potential Risk Factors for Poor Knowledge towards BA among studied Mothers of their ID Children with Bronchial Asthma.

Predictor variables	Standardized Coefficients B (Coefficient)	Odd's ratio	95.0% C.I.	P value
<b>Age (year)</b>				
6-	0.016	2.11	0.10-0.42	0.013*
12-		1		
<b>Mothers' educational Level</b>				
Illiterate/read & write	0.4012	14.82	3.71-15.5	0.001*
Basic education (Primary, preparatory)		8.36	4.23-12.3	0.001*
Secondary		1.68	0.36-2.36	0.071
University or higher		1		
<b>Occupation</b>				
Housewife	0.019	3.27	1.86-6.71	0.001*
Working		1		
<b>Monthly Income</b>				
Not enough	0.109	3.62	0.16-0.78	0.005*
Enough		1		
<b>Family History of BA</b>				
Yes	0.026	1		
No		1.24	0.46-3.13	0.161
<b>Duration of Bronchial Asthma</b>				
6 months -	0.087	4.73	2.65-9.58	0.001*
1 year -		2.06	3.14-7.24	0.009*
3 year -		1.23	0.15-2.1	0.147
6 years and more		1		
<b>Previous Hospitalization</b>				
Yes	0.0106	1		
No		1.98	0.14-0.73	0.030*
<b>Frequency of Hospitalizations</b>				
Once	0.1067	3.36	2.30-15.01	0.001*
Twice		2.14	3.11-12.8	0.012*
Three times and more		1		
<b>Have Rehabilitation Services</b>				
No	0.264	2.81	0.12-0.79	0.004*
Yes		1		

Dependent variables poor Asthma Knowledge, \* Significant effect at level 0.05  
C.I. confidence interval, P was calculated by multiple logistic regressions analysis

**Table (9): Multivariant analysis of different Potential Risk Factors for Poor Management towards BA among studied Mothers of their ID Children with Bronchial Asthma.**

Predictor variables	Standardized Coefficients B (Coefficient)	Odd's ratio	95.0% C.I.	P value
<b>Age (year)</b>				
6-	0.244	2.98	0.102-0.84	0.003*
12-		1		
<b>Birth order</b>				
First	0.0085	2.54	3.52-9.58	0.001*
Second		1.92	0.21-0.87	0.036*
Third or more		1		
<b>Mothers' educational Level</b>				
Illiterate/read &write	0.711	10.21	4.11-14.2	0.0001*
Basic education (Primary, preparatory)		3.14	1.25-3.58	0.006*
Secondary		1.26	0.12-2.11	0.154
University or higher		1		
<b>Occupation</b>				
Housewife	0.217	1.25	0.36-2.11	0.254
Working		1		
<b>Monthly Income</b>				
Not enough	0.374	2.76	0.12-0.79	0.003*
Enough		1		
<b>Family History of BA</b>				
Yes	0.147	1		
No		3.14	0.11-0.95	0.001*
<b>Duration of Bronchial Asthma</b>				
6 months -	0.652	4.25	2.25-12.8	0.0001*
1 year -		2.84	0.11-0.79	0.005*
3 year -		1.21	0.36-2.11	0.412
6 years and more		1		
<b>Previous Hospitalization</b>				
Yes	0.0071	1		
No		2.89	0.11-0.86	0.005*
<b>Frequency of Hospitalizations</b>				
Once	0.108	3.51	0.12-0.89	0.001*
Twice		1.24	0.36-2.11	0.411
Three times and more		1		
<b>Have Rehabilitation Services</b>				
No	0.275	2.94	0.103-0.75	0.003*
Yes		1		

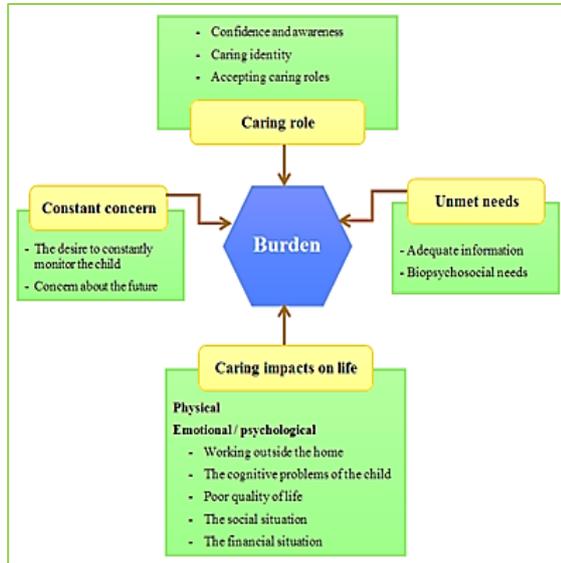
*Dependent variables poor Asthma Management*

*\* Significant effect at level 0.05 C.I. confidence interval*

*P was calculated by multiple logistic regressions analysis*

**Part (2): Results of Qualitative Data:**

The emergent themes are illustrated with quotations from participants. Each of the main themes is composed of several associated sub-themes that are described. **Figure (2)**



**Figure 2: Mothers' burden imposed by caring for intellectually disabled children with bronchial asthma.**

**Theme 1: Caring role:**

This theme comprises the inherent impressions of caring on mothers' confidence and awareness, identity, and acceptance of their caring roles. Participants also spoke about the rewards of caring including reaffirmation of relationships and fulfilment of self-worth.

**a. Confidence and awareness**

- Most mothers were aware of the causes of asthma:
  - انا عارفة أن الربو مرض تنفسي خطير، وسببه وراثي غالبا
- Mothers perceived themselves as more confident and acquired new abilities to identify symptoms, respond appropriately to acute assaults, and preserve these abilities over time. Being a first aider undoubtedly increased participants' confidence in care:
  - بحس إنني راضية عن نفسي لما انفذ التعليمات والخطة اللي قالي عليها الدكتور في حالة ان يجي له نوبة ربو
  - اكثر وقت باكون واثقة فيه من نفسي وقت لما بنتيجي له الازمة و اقدر الحقه و اتصرف صح
- While some mothers developed confidence, others found it difficult to believe in their own efficacy regarding their capacity to offer the care necessary for the disease itself.

- مش دايما باكون واثقة أني قادرة أساعد بنتي لما يكون عندها النوبة وخصوصا وقت الازمة

**b. Caring identity:**

- Many participants felt that their relationship with their children was fundamentally based on their caring role. Over time, several participants began to think of themselves as their "partner" or "supporting person." Others identified them as "carers", like health professionals. Furthermore, the majority of them remarked about how the scope of their caring responsibilities expanded when the severity of the children's symptoms increased or when a crisis occurred, such as sudden, severe attacks and/or a significant deterioration in health.

- أنا باشارك ابني في تعبته و باحس بيه و بوجعه و معاناته مش مجرد بأقدم له الرعاية اللي هو محتاجها

- لما كان تعبان قوي، كنت شايقة نفسي زي الدكتورة اللي بتعالجه

**c. Accepting caring roles**

- Most mothers embraced their caring role willingly; however, others expressed feelings of anger and resentment. Mothers shared that there was a strong desire amongst children not to become a burden in their own families and that they wanted to live with an improved quality of life.

- باحس اني مرتاحة و مبسوفة لما بخدم ابني و اقدم له كل اللي اقدر عليه

- الواحد بيعمل أي حاجة، علشان اللي بيحبه و ده ابني مش أي حد

- هو مش من السهل ان الواحد يفضل طول عمره بخدم شخص مريض و يفضل شايه همه و يفكر لو حصل له حاجة، مين حياكله و يخدمه و يشوف طلباته

- The majority of mothers were satisfied and trusted that all Allah brings is good.

- كل حاجة من عند ربنا. وأنا راضية بقضائه

- الحمد لله علي كل شيء لاني باشوف الولاد اللي ما شاء الله اللي صحتهم كويسة بيعملوا حاجات وحشة كتير زي شرب السجائر، علي الأقل ابني مش عاده الحاجات ده

- Some mothers wish that their condition is just a nightmare and everything is going to be over once they wake up

- اتمنى إنني اصحي من النوم و الاقي ان كنت في حلم و ان تعب ابني و مرضه كان كابوس و خلص

**Theme 2: Constant concern:****a. The desire to constantly monitor the child.**

- Mothers stated that their children's severe conditions were caused by their intellectual disability and bronchial asthma. Most of the participating mothers discussed their desire to

provide their children with all of the direct or indirect care they needed. Mothers indicated a desire to keep an eye on all of their child's daytime activities because they were concerned that the attacks might get worse because children with asthma frequently suffer from respiratory episodes. While some mothers struggled to focus at work because of worry and concerns about their children.

- علاج الربو مش سهل وبالذات لو كان الطفل معاق وخصوصا لو كانت إعاقة ذهنية وحكيون محتاج مجهود ووقت ان الام تقدر تفهمه ايه الحاجات اللي ممكن تضر صحته وكمان بيحتاج مجهود بدني من الام و صحة الام مع الوقت بتقل

- في فرق كبير في العناية بالطفل المعاق عن العناية بالطفل اللي عنده ربو بس، خدمة المعاق أصعب بكثير

- باقي خايفة قوي لأنني عارفة أن ابني ممكن يتعرض للاختناق أو ضيق في التنفس في أي لحظة. حاجة صعبة جدا بالنسبة لي، فما بالك كمان انه معاق ومش حيعرف يشتمكي اول ما يتعب

- وقت لما يجي له نوبة ربو بيبقي وقت صعب قوي عليا باسبب كل اللي ورايا وأفضل جنبه

- بيوصل بيا الأمر أحيانا أني احط أيدي علي صدرها علشان أتأكد إذا كانت لسه بتتنفس ولا ايه.

### b. Concern about the future

- Nearly all mothers were frightened about their child's uncertain future and believed that their intellectual disability together with asthma may influence their lives in the future.

- خايفة وقلقانة دايما و مش عارفة الوضع اللي انا فيه حيستمر لامتي لان لو حصل لي حاجة مين حيتكفل بيه و يراعيه كل ده بيخليني في حالة تفكير مستمر و مش باعرف انام

- The mothers' other concern was related to the adverse effects of the child's medication. They stated that because the child is still at a young age, unwanted and undesirable medication side effects may still impact him or her in the future.

- دايما بافكر في العلاج اللي بياخده ابني وانه حيكون له مضاعفات وممكن تأثر عليه في المستقبل و يكون وضعه أسوأ

### Theme 3: Caring impacts on life

The impacts of caring on participants' well-being varied, affecting everything from their health to their relationships, social status, and financial stability.

#### a. Physical

- Physical effects included fatigue and sleep disturbances, especially when the care receiver also had comorbid conditions, which made their role more challenging. Comorbidities made it more difficult for mothers to manage their

children's illnesses, creating escalating care. The mothers reflected on how their caring role explicitly affected his lifestyle.

- بنتني بتشخر بالليل و اوقات كتير كمان بتيجي لها النوبة بالليل و تبقي مش عارفة تاخد نفسها و مخنوقة علشان كده مش بأنام كويس بالليل و بأحس بالكسل و التعب و بأبقي ما ليش نفس و مش قادرة أعمل أي حاجة

- حاسة بالقلق و التوتر طول الوقت بسبب و من غير سبب و باعيط لاتفه الاسباب

- بأحس بضيق في التنفس بدون سبب واضح.

- اوقات كتير باقي ماليش نفس للاكل

### b. Emotional/ psychological

#### i. Psychological stress resulting from poor quality of life:

- Living with someone who has both asthma and an intellectual disability has a negative impact on the mother's emotional and psychological well-being. While for other individuals, feelings of uncertainty, helplessness, distress, fear, frustration, anger, and anxiety predominated.

- مش باقدر أتحكم في أعصابي وبتأعصب و انترفز لأتفه الاسباب و ده بيخليني اوقات مش باقدر اهتم بابني كويس

- أنت مش عارف كل يوم الصبح ايه اللي حيصصل له يتحس أنك مش قادر تعمل أي شيء ثم في اوقات كتير يتحس أنك لا حول لك ولا قوة.

- بأحس بأنني أتخلت عن حاجات و طموحات كتير أتمنيتها وكان نفسي اعلمها لكن ما حقتهاش بسبب حالة ابني

#### ii. Psychological stress resulting from the cognitive problems of the child

- Dimensions of the psychological and social pressures are reflected in the feelings of anxiety and tension that they encounter as a result of their disabled son's cognitive problems, which are noticeable as difficulties in understanding and paying attention, an inability to care for himself, in addition to his inability to adapt and deal with his siblings, peers, and family members, which makes dealing with them difficult for him and requires constant supervision and care.

- بسبب الإعاقة الذهنية اللي عند ابني، هو عنده مشكلة انه يعبر عن مشاعره و عن الاعراض اللي بيشتكي منها و كمان عنده مشكلة في استخدام البخاخة و مش بيقدر يعتني بنفسه كويس و كل ده بيضايقني جدا

- ابني عنده مشكلة كبيرة في التعامل مع اخواته و اصحابه و ولاد الجيران يعني مع كل اللي حواليه

#### iii. Psychological stress resulting from working outside the home

- Lack of control in circumstances resulting from having a kid with an intellectual disability and asthma at home, such as the challenge of finding

quality, inexpensive childcare, maybe one or many stresses that mothers must consider while deciding whether to work outside the home.

- ساعات كثير باغيب عن شغلي أو امشي بدري ومش باركز في شغلي بسبب حالة ابني ده غير اني باحس لني مقصرة مع اخواته لان هو محتاجني اكثر

- باحس اني مضغوطة من الشغل و كمان بأشعر بالتعب والارهاق بسبب شغل البيت ورعاية ابني التعبان و اخواته ،،،،،، حاسة ان صحتي مش قادرة تستحمل.

- ساعات كثير باقي متضايقه اني بعيدة عن ابني بسبب شغلي و باكون قلقانة طول الوقت عليه

#### iv. Psychological stress caused by the social situation

• Mothers struggle with society, which views a child's disability as a stigma or shame on the family and the mother. They also limit their social involvement due to the feelings of embarrassment caused by the presence of a disabled child in the family. Mothers live in a state of distress and tension and try to escape it in a way outside of the family environment.

- بأحس ان الناس مش بيراعوا مشاعر الطفل المعاق وده حاجة بتضايقني

- اشعر احياناً بالحرَج والارتباك بسبب تصرفات ابني بتكون غصب عنه و ما حدش فاهم هو بيتصرف كده

- حاسة ان حالة ابني وصمة في حياتي و حياة اخواته و عيلتي كلها

#### v. Psychological stresses resulting from the financial situation.

• The financial load grows as a result of the child's requirement for medical treatment. For instance, in the case of child follow-up, the cost of supplying medicine and good nutrition, as well as other supplies and needs that must be met, surpasses the family's financial capacity, which causes the mother to give up. All of these put the mother in a state of turmoil since she is unable to make plans for the future, particularly because her child cannot cope with life given his restricted abilities.

- تكاليف علاج ابني عالية قوي و مش في مقدرتنا

- باكون متضايقه اني مش قادرة او فر لابني كل اللي محتاجه كشف الدكتور و علاج، ده غير طلبات اخواته

### Theme 4: Unmet needs

#### a. Adequate information

• Mothers highlight the need for adequate information and counselling services to deal with their children's disruptive behavior and asthma management.

- بكون مش عارفة انا عطيت لابني البخاخ صح و لا لا،،،،، الدكتور بيشرح بسرعة و مش باكون فاهمة قوي

- محتاجين معلومات وبرامج الإرشادية تعلمنا أزاى نتعامل مع عيالنا و نعدل من تصرفاتهم

- عايزة أفهم كل حاجة عن حالة بنتي صحتها وتطوراتها.

#### b. Psychosocial needs

• The mothers struggle with unmet social and psychological needs. Mothers are in dire need to community support represented in the provision of centers and associations and specialists who are easy to turn to when needed. Furthermore, the most important need is the need for financial support, which is represented in the provision of appropriate medical treatment. In addition to allocating some financial privileges for the disabled and their families.

- محتاجين دعم مادي للأسر اللي عندها طفل معاق و بيعاني من الحساسية لان علاجه محتاج أدوية و متابعة

- باتمني يكون فيه تشجيع و دعم مش بس مادي لأ و كمان دعم اجتماعي و نفسي للام اللي عندها طفل معاق و كمان عنده مرض مزمن زي الربو، يعني مثلاً يكون فيه جمعيات و متخصصين الام لما تكون محتاجة حاجة تقدر تتواصل مع حد

- نفسي جوزي يقف جنبني ويساعدني ويقدر التعب اللي باتعبه مع ابني التعبان و باقي اخواته

- محتاجين نوادي لولادنا يرفهوا عن نفسهم ويمارسوا رياضة و تكون تحت اشراف متخصصين

### Discussion

Children with intellectual disabilities are a vulnerable population for asthma that has, up until now, received little attention in the medical literature. Although asthma should be managed similarly to other populations in accordance with guidelines for managing diseases in people with intellectual disabilities, there are some special considerations. Additionally, because of their comorbid conditions and cognitive impairment, they frequently need support managing their asthma (Davis, 2016; Erickson et al., 2018). This research adds important knowledge about both quantitative and qualitative data about the knowledge, management, and burden imposed on mothers of ID children with BA by bronchial asthma.

Worldwide, bronchial asthma is a widespread condition, particularly in industrialized nations where it has epidemic proportions. The incidence of BA was 7.7% in Egypt, where it is a major health issue for schoolchildren (Ghonem, 2022). The present study revealed that the age of ID children with BA ranged from 6 -15 years. Studies conducted in Egypt validated the current study, stating that the incidence of asthma is 9.4% in Cairo schools for students aged 11 to 15 and 8.2% in another study of children aged 3 to 15 years (Ahmad et al., 2016; Ghonem, 2022).

Asthma in children is more common in boys than in girls, as is well known. Boys' smaller airways, greater levels of airway tone, and maybe higher serum IgE levels in childhood are all likely contributing factors to the increased risk for boys (Liptzin et al., 2015). The present study revealed that more than half of them were boys. This result agrees with Abu-Shaheen et al. (2016), who reported that 62% of the asthmatic children were males. Moreover, a study conducted by Ghonem (2022) revealed that study male to female ratio was 1: 1.03 respectively without sex predominance.

Considering the family history of BA, more than one-third of children have a family history of BA. Similar to the study by Abu-Shaheen et al. (2016), reported that more than half of the studied children had a family history of BA. Results of this study revealed that the duration of illness after the first diagnosis was 6 years or more for less than half of the studied children. These findings corroborated those of Sangnimitchaikul et al. (2021) reported that children with asthma were commonly diagnosed 6.4 years on average after their first symptoms occurred, with the majority (73.3%) having had the condition for more than five years.

Regarding the health profile of the studied children, the results of the current study found that less than three quarts of the children had regular follow up, less than one-half of them were previously hospitalized and more than half of them were hospitalized only once. Additionally, avoidance of trigger factors and medications compliance were the most common preventive measures followed by mothers for the recurrent attack of BA. Bronchodilators and corticosteroids were the most frequent treatments used during an attack of BA, while more than half of the children couldn't use the inhaler independently.

In the **qualitative portion** of the present study, the most commonly mentioned themes that were perceived to be associated with the health profile of the studied children and the care provided for those children were mothers' desire to constantly monitor their children's condition, and that most mothers willingly accepted their caring role. These coincide with the relatively fair health profile of the children.

Better compliance and asthma management, which in turn leads to better control of asthma, are connected with patients' and parents' general knowledge about asthma and medications (Al-Binali et al., 2010). Likewise, children with asthma need carer skills such as recognizing symptoms, administering medicines, avoiding triggers, and implementing environmental control measures at home (Borhani et al., 2012).

The mother often assumes the primary duty of caring for the children in most families, which puts a lot of psychological burden on her (Borhani et al., 2012). In order to achieve better results for children's health, mothers of ID children with bronchial asthma must also be assessed for their knowledge and asthma management (Fasola et al., 2022). Besides, taking into account a child's disability and chronic illness enhances both the relationship and the quality of care provided to the child (Borhani et al., 2012).

The majority of the mothers in our study were housewives, married, and secondary educated. Their ages ranged from 35 to 40. Unfortunately, the results of the present study highlight some deficiencies in mothers' knowledge about asthma, as more than half of the mothers had poor knowledge and less than one-fifth of them had a good knowledge level. Nonetheless, concerning the total BA mothers' management score, it was found that more than two-thirds of the studied mothers had a poor management score, and the same percentage, less than one-fifth, had either a fair or a good management score. A significant correlation was found between mothers' knowledge and their management levels. Although some mothers throughout FGDs reported feeling more confident and acquiring new abilities to identify signs, respond appropriately to acute attacks, and preserve these abilities over time. Being the primary carer for children surely boosted their confidence in the system of care. This might be attributed to the absence of structured health education programs for families of intellectually disabled children with asthma. The results of the current study were in accordance with Al-Binali et al. (2010) and Nouredin et al. (2019) indicated a lack of asthma knowledge and a significant discrepancy between suggested and actual practices.

The results of the **qualitative portion** of the present study revealed that the most commonly mentioned themes that were perceived to be associated with barriers to asthma control were the physical and psychological burden imposed on the mothers. Also, mothers need appropriate information and counselling program to confront the disturbed behaviors of their children and how to deal with asthma. These coincide with the relatively poor scores of the mothers' asthma knowledge and management.

Results of the present study disclosed several potential risk factors for mothers' poor knowledge and management, including children younger than 12, an illiterate or read-and-write level of mothers' education, being a housewife, not having enough income, a 6 month to less than a one-year duration of bronchial asthma, either no previous hospitalization or few times of hospitalization, and a lack of rehabilitation services.

The results of the current study were in accordance with (Al-Binali et al., 2010).

For all parents, the early years of a child's life can be challenging ( El Sherbini et al. (2016). Nevertheless, caregiving for a person with ID and asthma may be demanding, and it may be burdensome to the parents' physical and psychological well-being (Majellano et al., 2021). Additionally, having a child with an intellectual disability with a chronic illness like asthma puts an excessive level of pressure on the family since it lowers the parents' quality of life (Borhani et al., 2012).

This study has provided insight into the experiences of mothers caring for children who have both ID and asthma. Theme related to **caring impacts on life** revealed the burden experienced by the mothers due to their children condition. Results of the current study revealed that families are severely impacted by mental impairment, especially mothers. This entails support with daily living tasks and self-care; all available information points to a significant burden brought on by this condition. This burden typically lasts the entire life. The mothers in the current study, the majority of whom claimed that they frequently felt overwhelmed by taking care of every member of the family, agreed that this had an adverse physical impact on the mother's body. They could experience several physical problems as a result of the challenge they need to overcome.

Additionally, the results of this study give insight into a crucial part of the social problems that mothers encounter, including stigmatization, social isolation, a lack of public awareness, and a lack of social support. Additionally, the mothers in the current study claimed that their families had rejected and not supported their impaired children.

Financial difficulties that interfere with different income-generating activities and additional expenses resulting from the existence of a disability, were another type of problem that mothers in the current study faced. The mothers also emphasized the cost of follow-up for the child to receive the necessary care. The present findings are supported by a study done by Kumar et al. (2021), and Singh et al. (2016) in which mothers of children with ID displayed lower physical health, impairment in social relationships, in their psychological state and poorer perception of their environment.

### **Conclusion**

Based on the findings of the present study, it can be concluded that more than half of mothers of intellectually disabled children with bronchial asthma had a poor knowledge score. Moreover, more than two-thirds of them had a poor

management score. Different potential risk factors for poor knowledge were the younger age of children, low level of mothers' education and low income. While potential risk factors for poor management were the younger age of children, firstborn child, low level of mothers' education, low income, and no family history with no previous hospitalization. Some mothers did not have confidence in their capacity to offer necessary childcare. Nearly all mothers were frightened about their child's uncertain future. Caring for intellectually disabled children with bronchial asthma negatively affects mothers' health, relationships, social status, financial stability, and emotional and psychological well-being. The mothers struggle with unmet social, psychological, and financial needs.

### **Recommendations:**

- 1- Raising the awareness of intellectually disabled children's mothers with bronchial asthma by school nurses about the definition of asthma, causes and risk factors, symptoms, triggers, diagnosis, medication, and complications.
- 2- Tailored asthma management training program by the school nurse, which will be designed for intellectually disabled children's mothers with bronchial asthma to address their needs and comply with the management of asthma action plan and childhood asthma control guide.
- 3- Professional, psychological, and social support should be provided by the school nurse to the mothers to reduce the burden of intellectually disabled children caring for bronchial asthma.
- 4- A protocol for intellectually disabled children with bronchial asthma caring between the Faculty of Nursing, Damanhur University and intellectual education schools in El-Beheira Governorate should be reinforced to accomplish and promote the health of students and their mothers.

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