Lived Experiences of Adolescents with Asthma: Struggle to Maintain Daily Life

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Abstract. Asthma in adolescence has various special aspects which are generally related to the process of growth and development and are also influenced by their perception of the disease. Objective: To explore lived experiences of adolescents with asthma in Medan, Indonesia. Methods: This was a phenomenological study where a purposive sampling of 12 adolescents living with asthma participated with in-depth interviews. The thematic analysis method was used to analyze the data. Results: Four themes emerged from the study data: 1) fundamental changes in daily life; 2) feelings of uncertainty; 3) tired of taking drugs; and 4) trying various traditional medicine. Conclusion: Adolescents with asthma experience struggle with feelings in life with limited normal activity, interrupted school activities, decreased social interaction with peers, confusion, feeling of discrimination, overwhelmed when bringing medicine to school, repeatedly taking medicine, feeling that they have never recovered.

Keywords: asthma · adolescence · Indonesia · feelings uncertainty · drug · social interaction · traditional medicine

1 Introduction

Asthma is a chronic disease that affects the quality of life, especially during adolescence [1]. Adolescents experience continuous and comprehensive changes and adaptations in the context of life as adolescence and generally can be exacerbated if the adolescent is diagnosed with asthma [2]. The changes and adaptations inherent in adolescence correspond to the stages of growth and development [3]. Where adolescents must deal with changes caused by disease and changes required by treatment. Asthma is also a family affair and impacts the lives of adolescents in several ways. It can lead to school absenteeism, low academic achievement, and emotional problems and interfere with the parents' daily life [4].

The burden of asthma is particularly high in adolescence, with an increased prevalence and mortality compared with younger children [5, 6]. For example, worldwide asthma affects 300 million people, and this is expected to increase to more than 100 million by 2025. On average 5–10% of the world's population suffer from asthma; however, 1/3 are under 18 years of age [7]. In Indonesia, the prevalence of asthma is 2.4% with the proportion of recurrence of 57.5% in 2018 [8].

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Besides, increasing prevalence of asthma has been linked to several health and lifestyle correlates, including the increasing technology and social media use by adolescents; asthmatic children have been found to use technology and spend more time on social media than non-asthmatics [9, 10]. At this stage of adolescence, there are changes, especially in physical and age maturity as well as hormonal changes. Adolescents will show their own identity and care about the views of others about them. Changes that occur in individuals during adolescence include physical, emotional, and psychosocial. The effect of changes on the pathophysiology, prognosis, and treatment of asthma should be considered carefully while treating adolescents [11].

Asthma in adolescents has several unique elements compared to the characteristics of asthma that will be seen by health workers in children or adults [12]. Asthma in adolescents must be accompanied by special consideration in assessing and managing it because of the increased risk of death from asthma [13], emotional, cognitive, and social changes, which can impact asthma assessment and management [14]. Therefore, having asthma in adolescence involves some struggles with an ambivalence between adapting socially, feeling well, and managing asthma [14] and living with asthma can negatively impact everyday life [15].

Based on the research it is found that adolescents experience negative emotions because of their asthma [16]; very high burden due to hospitalization and asthma-related emergencies [17]; anxiety and depression [18]; and stressful situations, such as disagreements with parents, teasing, or arguing, were associated with worsening asthma symptoms in the hours after the stressful events [19]; and insomnia sometimes make their stress situation worse [20].

Most adolescents have a problem with uncontrolled asthma [21]; poor adherence to medication because of which asthma exacerbations are more frequent [11]; uncontrolled asthma and improper asthma management [22]. These unpleasant experiences can affect the way adolescents perceive their treatment such as adolescents with asthma have a poor prognosis if there are delays in treatment due to failure to recognize the severity of illness or dependence on drugs have contributed to increased mortality [7]. Therefore, adolescents' opinions and beliefs about their health, and developing organizational skills and self-regulatory behavior can significantly contribute to adherence [23].

Many factors influence adolescents living with asthma, such as 1) family relationships in the treatment of asthma in adolescence; 2) adolescents with asthma and their peers; and 3) the role of schools for adolescents with asthma [2]; behaviors, belief, self-management, health literacy, the role of health provider, assessment of adherence, the role of caregiver, role of peers and the national asthma guidelines [24], and insight and understanding; asthma is not the focus of everyday life; recognized, and affected by asthma symptoms [14]. Also, contributing factors may relate to the knowledge, perception, and behavior of the adolescent about asthma.

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2 Method

2.1 Research Design

The design of this research is qualitative with a phenomenological approach that focuses on how a person experiences various things related to certain life experiences. Therefore, this phenomenological approach is expected to gain a deep understanding of the experiences of adolescents living with asthma in Medan, Indonesia. The purpose of this study was to explore lived experiences of adolescents with asthma. Selection of participants in this study used a purposive sampling method. The criteria for participants in this study were 1) adolescent, 2) history of asthma, 3) communicative, 4) willingness to become a participant stated verbally or by signing a research agreement, and 5) able to tell their experiences. The number of participants in this study amounted to fifteen people. Sampling in qualitative research is not directed at numbers, but based on the principles of suitability and adequacy of information until it reaches data saturation.

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2.3 Instrument and Data Collection

The data collection method used in this study was an in-depth interview. The interview process began with prolonged engagement with the participants. After participants confirmed they were willing to be interviewed, they were asked to read and sign the informed consent and fill in demographic data. Then the researcher began to conduct in-depth interviews using open-ended questions for no more than 60 min. The interview was stopped when it reached data saturation. The research was conducted in June - November 2020, starting from data collection until data collection was completed.

In-depth interviews are a way of collecting data through conversations and a question-and-answer process between researchers and participants which aims to gain knowledge about the meanings of a subject that are understood by individuals. This interview guide contains questions asked to participants, where the questions are made by the researcher herself.

This interview guide contains five questions consisted of 1) How do you feel after knowing that you have been diagnosed with asthma? 2) Does asthma affect your daily activities? 3) What actions do you take when an asthma attack occurs? And 4) What do you know about asthma? The next step is for the researcher to make a transcript of the results of the interview after each interview. Researchers grouped the data and described the data into narrative form. Data collection in this study was conducted on 12 participants.

Thematic analysis is a qualitative analysis method that is used to enable a data set to be organized and explained in detail. In this study, the thematic analysis approach of Braun and Clarke (2014) was used, comprising the following six steps: 1) becoming familiar with data, 2) generating initial codes, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes, and 6) producing the report. The triangulation methods used in this study were in-depth interviews, observations, and focus group discussions. Member checking was used to determine the accuracy of the findings in this study.

2.4 Ethical Approval

This study was approved by the Health Research Ethics Commission of the University of Sumatera Utara No. 164/KEP/USU/2020 and the informed consents were obtained in this study.

3 Results

3.1 Characteristics of Participants

Participants in this study consisted of 12 adolescents consisting of eight male and four female. Based on age range 11–14 years: seven participants (58%) have junior high school education: seven participants (58%) were Acehnese: five participants (41.6%) were living with parents: 12 and 12 participants (100%) did not receive asthma education in schools (Tables 1, 2, 3, 4 and 5).

3.2 Analysis Findings

Four themes emerged from the data:

- Fundamental changes in daily life
- Feelings of uncertainty
- Tired of taking drugs
- Try various traditional medicine

Theme 1. Fundamental changes in daily life.

Table 1. The characteristics of the participants (n.12)

Characteristics of Participants	Frequency (f)	Percentage (%)
Gender		
– Male	8	66.6%
– Female	4	33.4%
Age		
– Early adolescence (11–14 years)	7	58%
– Middle adolescence (15–17 years)	5	42%
Education		
– Junior high school	7	58%
– Senior high School	5	42%
Ethnic group		
– Acehnese	5	41.6%
– Bataknese	3	25%
– Javanese	2	16.6%
– Malaya	2	16.6%
Living with parents		
– Yes	12	100%
Asthma education in schools		
– None	12	100%

Table 2. Themes, Subthemes and Participants' Quotes (n.12)

Themes	Subthemes	Participants' quotes
Fundamental changes in daily life	Limited normal activities	"If I run or walk so easily get tired, the point is I can't get tired. If I'm tired of breathing heavily if forced to take a deep breath it turns into a cough," (P.6) "For example, like at school, we have running sports activities, so… I said to the teacher, I didn't want to participate…. I said that running is short of my breath." (P.1) "I can't do much like my friends in general. Because tired a little immediately shortness of breath… Growing asthma. " (P.9)
	Interrupted school activities	"Yes, sometimes at school asthma relapsed because of the cold. The chest feels full and heavy when breathing. If it's like this people are confused. I have to call asking to pick up at school." (P.5) "It was chaotic at that time, only two of our teachers were participating in sports activities. They were shocked and scared when my asthma relapsed. Then I was taken to the community hospital near the school." (P.7) "If you have a cold and a cough that immediately recurs, yes, it becomes difficult to breathe. The narrow channel is like a narrow so much liquid that there is no channel like it is closed. When it was like this, the teacher ordered me to go home." (P1)

(*continued*)

Table 2. (*continued*)

Themes	Subthemes	Participants' quotes
	Decreased social interaction with peers	"You can't go anywhere, if you go out you have to wear a mask and wear a jacket. Don't go out carelessly. So I didn't go anywhere, only at home if I didn't need to leave the house." (P.8) "At first, I didn't know… But because of frequent relapses due to playing outside with friends when it was cold… For a long time I thought that if I was cold, it would have recurred this tightness. Since then, I don't want to go out of the house often to meet with friends, afraid that the congestion will relapse… it hurts even though." (P.10) "Forbidden by mom when playing with friends outside the house, mom is afraid that her shortness of breath will recur epee…. What is it. Sometimes I really want to play but I am afraid of relapse if it recurs, the breath sounds like… Ngik… Ngik… That's the point." (P.1) "Even playing with friends outside, I reduced it first, that's it….. Don't play too much outside…… at home, I'm afraid of being hit by ash and cold winds so just stay at home." (P.11)

This theme had three subthemes:

- Limited normal activities refer to easily tired and shortness of breath doing activities.
- Interrupted school activities refer to asthma relapse and admission to the hospital.
- Decreased social interaction with peers refer to limiting playing outside the house and rarely playing with friends.

Theme 2: Feelings of uncertainty.

Table 3. Themes, Subthemes and Participants' Quotes (n.12)

Themes	Subthemes	Participants' quotes
Feelings of uncertainty	Confused	"I heard that I was afraid that something would happen, that asthma can cause people to die." (P.12) "Confused and afraid that something will happen and continue to be sad and mixed up, afraid that when I sleep, I won't wake up again." (P.10) "I feel that having asthma cannot heal. Recovering can continue to be shortness of breath again like that and continue to have shortness of breath for the rest of his life." (P.4)
	Feeling of discrimination	"During extracurricular activities, I am often not allowed to participate, yes I sit around like that at school, because I can't do activities like other friends. Because I get tired easily and asthma recurs." (P.9) "I am prohibited from participating in extracurricular activities such as swimming in school because swimming can be tight, right swimming so I have to hold my breath." (P10) "I just run a little, I'm not strong and struggling, that's why my mother always thinks I'm weak and get sick easily. Always worried if I played away like that." (P.8) "There are also friends who stay away because I have a disease like that. Yes, if friends who know like to comment, I'm sorry to see you. Come on, let's go home… You can't be tired, can't be caught in the wind, and just run for a little bit is already short of breath." (P.6) "Like to be banned by friends if I want to play. Like being told, your asthma will recur. Make us confused and bothered to help you, you know." (P.9)

This theme had two subthemes:

- Confused refers to fear that something will happen and feel that things cannot get well.

- Feeling of discrimination refers to not allowed to involve in extracurricular activities, considered weak, and underestimated

Theme 3: Tired of taking drugs.
This theme had three subthemes:

- Overwhelmed when bringing medicine to school.
- Repeatedly taking medicine.
- Feeling to have never recovered.

Theme 4: Try various traditional medicines.
This theme had three subthemes:

- Consume honey
- Taking garlic
- Taking ginger

4 Discussion

The findings of this study highlight a number of crucial areas of concern for adolescents with asthma within the core areas of their lives: 1) Fundamental changes in daily life, 2) Feelings of uncertainty, 3) Tired of taking drugs, and 4) Try various traditional medicines.

4.1 Fundamental Changes in Daily Life

Asthma in adolescents has an impact on daily life [25]. In adolescents with asthma, recurrence can occur anywhere, including when they are at school; the more frequently asthma relapses occur, the more fatal the consequences will be so that it affects important activities such as school attendance, limited activities, and disrupted social interaction with peer group [11]. Several studies have considered having asthma can reduce the quality of life by limiting activities. Some studies found that physical activity is limited in children with asthma [26] because of fear of an asthma attack emerging [27]; and fear that it may trigger the disease [28]. Another factor that affects adolescents is described as the motivation for physical activity, such as teachers' lack of asthma knowledge, embarrassment over asthma symptoms, not being able to keep pace with peers, seasonal challenges, and mastering fun physical activities [29].

School absenteeism can affect the learning process negatively and children with asthma seem to have a higher school absence rate than their healthy peers. Halwani et al. (2016) found emotional aspects and feeling frustrated because unable to keep up with others, decreased social activities, and poorer school attendance relative to intermittent asthmatics. Uncontrolled asthma has interference with play, domestic work, fear of dying anytime, and feeling of being a burden [30]. Therefore, educational interventions in schools raise the awareness of asthma and weaken the impact of morbidity indicators [31]. Stimulating positive illness perceptions and medication beliefs might improve adherence, which, in turn, might lead to improved disease control and better quality of life [32].

Table 4. Themes, Subthemes and Participants' Quotes (n.12)

Themes	Subthemes	Participants' quotes
Tired of taking drugs	Overwhelmed when bringing medicine to school	"Lazy to bring equipment and medicine to school is such a hassle. Sometimes if my asthma recurs, I ask to go home." (P.5) "If I always depend on medicine, it's difficult and troublesome. Sometimes I am also embarrassed when I see friends always bringing drugs to school. Like a sick person." (P.3) "I feel bothered and ashamed to bring drugs to school, especially since there are many drugs that must be inhaled through a nebulizer, salbutamol and Ventolin, cough medicine, and antibiotics. It's sad to have asthma… How come this feels like this time." (P. 8)
	Repeatedly taking medicine	"I didn't even get sick; I took the medicine so it didn't come back. After being injected, when I got home, I was told to take medicine morning, noon, and night. Sometimes twice a day, depending on the medicine." (P.3) "I have taken medicine but the pain doesn't heal either…. Just tired of taking medicine." (P.10) "Sometimes I have to take up to 3 or 4 kinds of medicine every day. So inject drugs at the clinic and given medicine too. Well… I was told to drink. Yes, when it's good. Yeah.. Don't drink it."(P.4)
	Feeling to have never recovered	"If I can't stand the shortness of breath, then I want to get an injection. After being injected several nights, I still felt short of breath. Sometimes I even cry. It hurts to feel the pain of gasping for breath, it's hard and it's hard to breathe." (P.6) "Just get sick and get in and out of the hospital. Yes, yesterday I took medicine and was injected to recover for a while then recur again and again like that… but it didn't heal either." (P.5) "The proof is that I am not getting better… relapses… recurrences. If I had a cold, my asthma recurred, I didn't know what else to eat… Everything was wrong, I had the medication, but it still recurred. The disease should have been severe, if it wasn't severe, it wouldn't recur…. That means it's severe." (P.7)

Table 5. Themes, Subthemes and Participants' Quotes (n.12)

Themes	Subthemes	Participants' quotes
Try various traditional medicines	Consume honey	"My mom told me to drink honey every day." (P.12) "Usually before going to bed, my mom told me to drink honey mixed with warm water and lemon." (P. 2) "Every day I drink two tablespoons of honey mixed with orange juice." (P.12)
	Taking garlic	"If my asthma recurs, make a soup mixed with garlic so it won't be difficult to breathe and dilute the mucus." (P.6) "Once my mother gave me a warm drink from a mixture of garlic and milk." (P.1) "I drink garlic water soaked in hot water." (P.11)
	Taking ginger	"I drink boiled ginger water three times a day. One drink half a glass." (P.1) "My mother once gave me warm ginger water to drink, because we Javanese believe it can cure asthma." (P.10) "I drink ginger water mixed with one tablespoon of honey. My mother told me to drink 1 tablespoon every day 2 to 3 times." (P.6) "Yes, boiled ginger with brown sugar and then drunk." (P.8)

4.2 Feelings of Uncertainty

Feelings of uncertainty are undecided, unknown, or doubtful in some way. Isroni et al. (2020) described uncertainty can be as psychological factors, such as learned helplessness, emotional state, and cognitive distortions. Later, the consequences of uncertainty are anxiety, depression, fear, agitation, and anger. From several studies, it was found that various adolescents described their feelings related to asthma. Jonsson et al. (2017) found that feeling of uncertainty is reflected in the teenager's understanding of their disease but, on the other hand, they ignore and deny their asthma symptoms Chen et al. (2015) found feelings of uncertainty during illness, feelings of chaos and instability and social tension, and family conflict. Illness uncertainty may be an important factor that influences psychological functioning and distress and coping in the context of pediatric chronic illness [33]. Adolescents reported predominantly negative feelings associated with their symptoms such as afraid, challenging, difficulty, frustration, panic, scared, sad, upset, and like crap [34]; frustration, being left out, anger, worry, concern, discomfort, and fear from asthma attacks [15]; arguing, bullying and sad feeling had lower

flourishing [42]; and depression and suicidality [35]. These conditions must be managed wisely in order to keep a strong mind for treating the disease and their symptoms [36].

4.3 Tired of Taking Drugs

Adolescents with asthma have significant difficulties in life. The task of managing a chronic medical condition or taking medication in front of peers may cause embarrassment or self-consciousness. Adolescents can harbor unique views on their medications, causing them to be distrustful of taking medications. Lack of education and negative perceptions about treatment and providers also frequently influence adherence [23]. Adolescents mentioned a lack of perceived need or beneficial effects. Complicating this already difficult time with a long-term chronic condition such as asthma can often seem overwhelming for the young person and requires a skillful approach to management, which is specific to adolescents [37]. Most of the asthmatic patients had negative self-estimation for their quality of life and how it requires a complex therapeutical approach [38]. Adolescents become more independent and want to be responsible for taking their medication, but sometimes forget g to take it or are embarrassed to take it in front of their friends [23]. Identifying the reasons for poor disease control and adherence is essential to help improve patient quality of life [23]. Amin et al. found that, due to the episodic nature of asthma, many patients felt that their daily life was not substantially impacted; consequently, many harbored doubts about the accuracy of their diagnosis or were in denial about the impact of the disease and, in turn, the need for long-term treatment. Lycett et al. found that several factors influence asthma patient adherence such as patients' beliefs about their necessity for treatment, social stigma, and embarrassment contributed to poor adherence. There is evidence that symptoms of depression also contribute to increased risk for poor medication adherence [39] and accepting the need to take treatment but being particularly concerned about side-effects of oral corticosteroid [40].

4.4 Try Various Traditional Medicines

Individual beliefs about medication use may be influenced by a host of factors, including culture, individual preference, and family experience, all of which likely affect patient acceptance of controller medications when prescribed [39]. In addition to using medical treatments specifically for asthma sufferers, the properties of natural ingredients are also able to relieve asthma. Sadr et al. revealed that compound honey syrup can be a safe and effective complementary drug for the treatment of pediatric asthma; Chinese herbal medicine therapy reduced the risk of consequent asthma hospitalization [41]; and conventional treatments plus acupuncture are associated with significant benefits for adolescents [42]. Honey alone has no strong evidence to support its effectiveness in controlling asthma; however, when used in a combination with other substances, it showed relatively high efficacy in patients with asthma [43]. Jalali et al. found that ethnobotanicals were the most efficacious medicinal plants for the improvement of asthma [44]. This study demonstrated that, in children with intermittent asthma, a short-course administration of an herbal mixture at the onset of viral respiratory tract infection results in a significant reduction in day cough, night cough, and night awakenings.

5 Conclusion

Adolescents with asthma face great challenges in living their lives with asthma. Knowledge related to self-management of asthma properly and appropriately can reduce the nightmares they experience in daily life such as fear, feelings of uncertainty, discrimination, and limited interactions with peers.

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Setiawan carried out the study design and data collection.
Nur Asiah carried out the data collection.
Nur Asnah carried out the literature search.

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Availability of Data and Material. The authors declare that all otherdata supporting the findings of this study are available within the article.

Declaration.

Ethical Consideration. This study was approved by the Health Research Ethics Commission of the University of Sumatera Utara No. 164/KEP/USU/2020 and the informed consents were obtained in this study.

Conflict of Interest. The authors declare no conflicts of interest regarding the publication of this paper.

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