



Experiences of Daily Life Among Adolescents With Asthma – A Struggle With Ambivalence



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ABSTRACT

Objective: There is limited knowledge about how adolescents with asthma view their disease in daily life and how these views impact on management. The aim of this study was to describe experiences of daily life, with particular focus on thoughts, feelings and management of adolescents with asthma.

Methods: In this qualitative study, data were obtained from 10 interviews with adolescents (aged 16–18 years) with asthma recruited from the Swedish population-based prospective birth cohort, BAMSE. Data were analysed through Systematic Text Condensation.

Results: Experiences of daily life among adolescents with asthma were defined in four categories: *Insight and understanding; Asthma not the focus of daily life; Being acknowledged* and *Being affected by asthma symptoms*. The adolescents had developed an insight into and understanding of their disease, but did not want asthma to be the focus of their daily lives. The adolescents wanted their asthma to be acknowledged, but not to the point that they were defined by their asthma. They reported having many asthma symptoms, especially during physical activity, but also described a desire to feel healthy, “normal” and like their peers.

Conclusions: Having asthma in adolescence involves several struggles with ambivalence between adapting socially, feeling healthy and managing one's asthma.

Implications in Clinical Practice: The provision of person-centred care may be one way to handle the ambivalence among adolescents with asthma and thereby help them to manage their asthma.

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Introduction

Adolescents with a chronic disease may experience stresses and challenges beyond those associated with normal development (Bitsko, Everhart, & Rubin, 2013; Rhee, Wenzel, & Steeves, 2007). Asthma affects an estimated 7–10% of adolescents in many western countries (Mallol et al., 2013) and is one of the most common chronic diseases in this age group. During adolescence, the young person gradually develops independence from his or her parents, whereas peer groups become increasingly important (Towns & van Asperen, 2009). In later adolescence, young people develop abstract reasoning skills and think more about

aspects of the future, such as work, lifestyle and relationships (Towns & van Asperen, 2009).

Asthma medicines and increased medical knowledge have advanced the care of people living with asthma. Yet, asthma during adolescence can be particularly difficult to treat (Bitsko et al., 2013). Adolescents with asthma often have poor adherence to prescribed inhaled corticosteroids (Blaakman, Cohen, Fagnano, & Halterman, 2014; Koster, Philbert, de Vries, van Dijk, & Bouvy, 2015) and often develop their own strategies for coping and dealing with medical treatment and adapting to asthma management (Jonsson, Egmar, Hallner, & Kull, 2014; Rhee et al., 2007). Unsurprisingly, many adolescents often report ongoing symptoms and impaired quality of life (Carroll, Wildhaber, & Brand, 2012; Jonsson et al., 2016). At the same time asthma management in adolescence is much more than pharmacological treatment (de Benedictis & Bush, 2007; Horak et

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al., 2016; Srof & Velsor-Friedrich, 2006; Towns & van Asperen, 2009). The adolescents have to deal with environmental, psychological, physiological and social factors which may affect daily life and how they perceive and manage their asthma (Mammen, Rhee, Norton, & Butz, 2016; Rhee, Belyea, Ciuzyński, & Brasch, 2009). Mammen et al. showed that adolescents' normalized their asthma symptoms and their reported symptoms are based on perceived symptoms severity and adolescents' concepts of normalcy relative to personal baseline (Mammen et al., 2016). Unfortunately, asthma guidelines fail to take many of these factors into account ("The Global Strategy for asthma management and prevention. <http://ginasthma.org/>, updated 2016") (Ekstrom et al., 2015).

Adolescence also involves a shift from parental control to self-control, which further potentiates risk for poor asthma control: low adherence; ignoring symptoms and/or forgetting to take asthma medication (Blaakman et al., 2014; Srof & Velsor-Friedrich, 2006). Beyond that little is known about how adolescents view their asthma in daily life and how this may have impact on their self-care and disease management.

Qualitative research provides useful methods for gaining knowledge about the complexity behind attitudes and experiences (K Malterud, 2014). Therefore, we aimed to describe experiences of daily life, with particular focus on thoughts, feelings and management of adolescents with asthma.

Methods

A qualitative approach with individual interviews was used to capture the adolescents' experiences of daily life with asthma.

Participants and Settings

Participants were adolescents with asthma and were recruited from the Swedish population-based prospective birth cohort, BAMSE (Wickman, Kull, Pershagen, & Nordvall, 2002). This birth cohort consisted of 4089 children born between 1994 and 1996 in predefined areas of Stockholm. BAMSE is the abbreviation for the Swedish title of the overarching cohort, Children, Allergy, Environment, Stockholm, an Epidemiological study. Information on environmental exposures, socio-economic status, and family history of allergic disease was obtained when the children were approximately 2 months old (baseline). Follow-up questionnaires focusing on symptoms related to asthma and other allergic diseases, as well as key exposures and lifestyle factors, have been obtained at regular intervals (1, 2, 4, 8, 12 and 16 years).

In the present study adolescents were classified as having asthma if at least two of the following three criteria were fulfilled.

- Symptoms of wheezing in the last 12 months,
- Doctor's diagnosis of asthma ever,
- Asthma medicine occasionally or regularly in the last 12 months (Ekstrom et al., 2015).

At the clinical examination at 16 years, blood was collected and analysed for specific Immunoglobulin (IgE) antibodies to common airborne and food allergen.

The definition of current asthma used in the present study was consistent with that used in many BAMSE studies (Ekstrom et al., 2015). To further characterise the study population, we also considered asthma phenotypes. Persistent disease was defined as having the disease of interest at the first age interval (1, 2 and/or 4 years) and still having the disease at 8, 12 and 16 years old. Late-onset phenotype was defined as being disease free at the first years (1, 2 and 4 years) and only having the disease at the latest age interval (8, 12 and 16 years) (Ekstrom et al., 2015; Hallberg et al., 2015).

Requests for participation were made in two steps. In the first step, a research nurse compiled a list of all adolescents fulfilling the criteria for asthma ($n = 357$) at the 16-year follow-up. She contacted one person

out of each 20, which gave a total of 18 possible interview persons. The nurse asked the 18 prospective participants if the first author could contact them and inform them about the study. This was done so the adolescents would not feel compelled to participate. In the second step, the first author contacted the 18 participants and ten of them agreed to participate in an individual interview and eight declined. The selection was made to identify adolescents who wanted to tell their story of what daily life was like with asthma. Our asthma criteria provided the opportunity to capture adolescents with differing asthma severity and thus possibly varied answers. The adolescents who agreed to participate and their parents received both oral and written information about the study and gave written consent.

Data Collection

Data were collected through 10 individual interviews with a semi-structured interview guide focused on thoughts, feelings and management in daily life (Table 1). To glean a deeper understanding of daily life, we included questions with four common themes: body, relationships, time and environment, which can jointly be seen as the basis for how humans perceive their lives (van Manen, 1997). Questions were occasionally supplemented with follow-up questions for clarification (Patton, 2002).

All interviews were performed by the first author in the medical clinic where the adolescents underwent a clinical examination as part of their participation in BAMSE. Before starting the interviews, adolescents were informed that their participation was voluntary and that they could cease participation at any time. The interviews, each of which was approximately 1 h long, were tape-recorded and transcribed verbatim. Interviews were conducted and analysed in Swedish and the central quotations were translated into English.

Analysis

The analysis was performed with Systematic Text Condensation (STC) in accordance with Malterud (K. Malterud, 2012). STC is a qualitative descriptive approach, presenting the experiences of the participants as expressed by themselves (K. Malterud, 2012). The goal for STC is to present vital examples from people's everyday life experiences and search for the essence of the experienced phenomena.

The analytical process of STC involves de-contextualisation and re-contextualisation (an oscillation between the parts and the whole) (K. Malterud, 2012). In the former, pieces of data are lifted out and closely examined (Fig. 1, Steps 1–3), and subsequently integrated into common

Table 1
Interview guide.

Topics relating to daily life with asthma covered during interview	Sample questions
The body	How did your asthma start? How does asthma affect you? How does it feel? What do you do when asthma affects you? How do you handle the situation?
Relationships	How does asthma affect your relationships with friends, teachers, parents, coaches, and/or relatives? Describe meeting with healthcare professionals.
Time	What was it like when you became ill with asthma? What is it like now? What are your thoughts about the future?
Environment	How is your asthma when you are exposed to: indoor air, outdoor air, sports, leisure, perfumes, tobacco, cold, heat, forests, nature?
Life as an adolescent	What is it like to be an adolescent with asthma?

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