

**Thesis title: The social environment of asthma management in early adolescence**

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**Abstract**

For adolescents with asthma, adhering to asthma regimes implies not only taking medications to *relieve* asthma attacks, but also adjusting their life styles in order to *prevent* asthma attacks. These life style modifications, such as avoiding allergens or having to limit physical activity, sometimes force adolescents to compromise their social life. On the other hand, the impact of such life style modifications on their social life may in turn force adolescents to give up adhering to asthma regimes. Indeed, adolescents are learning to be more independent while they enjoy a more complicated social life at home and at school than previously, and this rapid social development may thus be a great life challenge to adolescents with asthma. This thesis reports four studies which investigated the relationship between multi-dimensional asthma management (in medication and life style regimes) and the social life of young people with asthma at the transitional age from childhood to adolescence (or early adolescence, age 9-14), which also marks the transition from primary school to secondary school.

In line with the literature on other adolescent chronic illnesses, study 1 demonstrated a downward trend of multi-dimensional asthma management in early adolescence. This developmental change was further investigated in study 2, 3 and 4, in which theories in behavioural psychology were followed to emphasise human behaviour influenced by the social activities and social relationships in the living environment, or the *social environment*. This was supplemented by theories in developmental psychology to identify relevant aspects of the social environment in early adolescence, especially the social relationships with parents, school staff and peers. Using quantitative and qualitative approaches, the studies not only supported the direct influence of asthma-specific social support, but also explored some mechanisms with which social relationships influenced asthma management in a more subtle and context-dependent way. By approaching asthma management behaviour with theories from behavioural and developmental psychology, it is also hoped that this thesis could be an example that shows the importance of recognising and to understanding the social life of young adolescents when adolescent behaviour is concerned.



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## **Chapter 1**

### **Introduction: Addressing the gaps**

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Asthma is a major global health problem for children and young people. Despite advances in medical technologies in the diagnosis and treatment of asthma, these medical technologies need to be accepted and understood by patients so that they can adhere to the medical regimes prescribed for them (Sokol et al., 2005a; Osterberg and Blaschke, 2005; Burkhart et al., 2007a; Sokol et al., 2005b; Lim et al., 2008). Therefore, improving the extent to which children and adolescents adhere to medical regimes, or improving *adherence*, is an important topic in social science as well as in the biological sciences.

Although there have been a number of studies published around this topic, this thesis seeks to address three gaps observed in the literature between what we know and do not know.

*The first gap: lack of adherence information on behavioural management*

The first gap is related to an excessive focus in the literature on adherence to asthma medications. Childhood or adolescent asthma, like other chronic illnesses, is not a curable disease. All we can do is try our best to control the disease and prevent its progression. In most cases, asthma control relies more on the management behaviours that help to eliminate the allergic sources than on the medications alone (Wolf et al., 2002; Madge et al., 1997; GINA, 2007; NHLBI, 2007). By contrast, the current literature focuses much more on medication adherence than on behavioural adherence (McQuaid et al., 2003; Burkhart et al., 2001; Colland et al., 2004). This may be due both to the dominant medical background of the researchers, and to the perception of the relative objectivity of the measurement of medication adherence.

However, it is possible that the perception of this objectivity of measuring medication adherence may be biased. Pill counts or machine monitoring, although

used to measure medicinal adherence, are still psychometric measurements. The machines can only be reliable in a mechanical way (e.g. how many times the puff was squeezed), not a psychological way (e.g. how many times the patient actually took the puff). Therefore, the current measure for the thesis includes all asthma control behaviours that matter, rather than focusing on a single medication dimension of asthma control. The limitations of psychometrics remain, but with cautious treatment, it is hoped that the results will provide us with a more holistic picture of asthma adherence that will inform clinical or school practice.

*The second gap: lack of application in developmental psychology*

A second gap in the literature can be seen in the difference between the literature on adult patients with asthma and adolescent patients. Although childhood and adolescent asthma shares similar properties with other adult chronic illnesses, the application of theories of health psychology cannot be transferred directly from adult to younger patients. Adolescents depend on their parents in different degrees; they are increasingly experiencing a broader environment (compared to the family environment), and still learning to make decisions and solve problems more independently. This development may make adolescent behaviour different from adult behaviour. Therefore, in addition to the theories of health psychology, this thesis considers young adolescents' developmental change in the context of asthma management.

*The third gap: lack of direct evidence on young adolescents' independent behaviour*

Quantitative studies on young adolescents' adherence are highly dependent on parental reports, in which case young adolescents are presumed to be well-understood by their parents (McQuaid et al., 2005; Gavin et al., 1999). This is not always true. As children and young people gradually spend more time in school with their peers, their

parents cannot be knowledgeable about their behaviour at all times. Therefore, it is not sufficient only to investigate how asthma is managed *for* young adolescents; how asthma is managed *by* young adolescents is also important. Recently, some qualitative studies have been conducted to investigate the perspectives of children and young adolescents in asthma management (Penza-Clyve et al., 2004; Burkhart and Ward, 2003; Pradel et al., 2001; Buston and Wood, 2000; Williams et al., 2008; Warnes et al., 2005). Following these studies, this thesis reports research (qualitative and quantitative) focusing on adherence behaviour and the beliefs of young adolescents, whose thoughts are sometimes not disclosed to their parents.

It was an advantage for the researcher to bring his background in medical and health sciences into the education research networks, which were already sophisticated in a variety of adolescent issues. Although this thesis focused on young adolescents with medical illnesses, it was based on theories of young adolescent behaviour derived outside the health area. Therefore, the theoretical framework may be applied not only in medical practice, but may also be useful to those who work with young adolescents, especially school teachers and special educational needs coordinators (SENCOs).



**Chapter 2**  
**Leading an early adolescent life with asthma**  
Asthma management in early adolescence



This thesis focuses on young people between the age of 9 and 14 years (or year 5 to year 9 in mainstream UK education). Just like the uncertainty they feel about themselves at this age, there is no proper term to describe the transition between childhood and adolescence. To school teachers or psychologists, a 9 year old child may seem too young to be an adolescent. To paediatricians, however, physiological puberty that starts as early as 8 years old in girls and 9 years old in boys can be normal, and usually it is agreed that the age span between 9 and 14 years is related to the earliest signs of biological, psychological and social development in adolescence (Coleman and Hendry, 1999; Kliegman et al., 2007). Therefore, this thesis uses the term *early adolescence* or *young adolescents* to describe this transitional period between childhood and adolescence.

“Asthma management in early adolescence” is a topic in the intersection of two theoretical routes. Asthma management is practical knowledge, which is usually of interest to people with medical backgrounds. To medical practitioners, early adolescence can just be a period of hormonal and growth transformation. Their psychological and behavioural changes are sometimes less of concern. On the other hand, most other people who work with young adolescents, especially educationalists, are concerned about school achievement and behavioural problems. Medical adherence is generally outside of their main focus. Standing at this intersection and examining the encounter of the two disciplines, medicine and education, this chapter starts with the context of asthma management and its relevant issues in early adolescence.

## **2.1 Being a young adolescent with asthma**

This section does not provide a review of cutting-edge pathogenesis or immunologic evidence of childhood or adolescent asthma. Instead, literature is

reviewed in order to describe how people with asthma live their lives, or how it is to live with asthma. Further information on the biological and epidemiological review of asthma can be found in the latest report from the Global Initiatives for Asthma, from the House of Commons Health Committee, UK, and from the National Heart, Lung and Blood Institute, USA (GINA, 2007; HCHC, 2004; NHLBI, 2007). Alternatively, information for non-professionals can be found on (or requested from) the websites of AsthmaUK ([www.asthma.org.uk](http://www.asthma.org.uk)).

### **Living with asthma**

It is difficult to find a primary or secondary school teacher who has never seen a student with asthma in his or her class. Approximately 15- 20% of children and adolescents in the UK suffer from asthma, and between 5% and 30% worldwide (Hasnain et al., 2009; Patel et al., 2008; Calam et al., 2005). Asthma is the most common chronic health condition in childhood and adolescence in developed countries. It can develop at any stage of childhood, adolescence or adulthood, and many of those who “grow out of asthma” may still find their symptoms returning later in adulthood, suggesting that the underlying disease seems to persist (GINA, 2007).

People with asthma can usually be recognised when they have an asthma attack. An asthma attack is an episode of small airway narrowing. Some people start with having only minor symptoms -- they may have wheezes or coughs at night, or feel less competent in aerobic exercises. However, any minor asthma attack which is ignored can potentially develop into difficult breathing, then even into a life-threatening suffocating catastrophe within minutes to hours. Because it is difficult to define people who have ever had asthma, who have current asthma and who have current asthma but well controlled, there is no reliable epidemiological figure to estimate the number of children or adolescents suffering from asthma attacks (Gupta et al., 2004; Robertson et al., 1998). Meanwhile, because asthma can be under-

diagnosed or some asthma attacks are not known to adults, adult-reported asthma treatment may under-estimate the incidence. On the other hand, adolescent-reported wheezing symptoms may over-estimate the incidence because many wheezing symptoms may not be due to asthma. Nevertheless, there have been several surveys carried out in the UK. In a school based research study in South East England, the school-reported asthma prevalence was 8%-11% in children aged 7-9, while parent-reported asthma prevalence was 24%, and 17% of parents reported asthma treatment within the past 12 months (McCann et al., 2002). Instead of adult-reported asthma, adolescent-reported wheezing symptoms were investigated in another survey in North East England. In this survey, 22-27% of adolescents (age 13-14) reported that they had had asthma at some time, 29-34% of adolescents reported that they had ever wheezed, 21%-23% of adolescents reported that they had wheezed in the past 12 months, and 4-9% of adolescents reported that they had wheezed more than 3 times in the past 12 months (Shamssain, 2007). Therefore, the incidence of asthma attacks also depends on the definition of asthma in epidemiological surveys.

The impact of asthma is not simply physical. In a large UK survey, children and adolescents (age 5-15) from a nationwide representative sample, their teachers and their parents completed questionnaires on adolescent mental health. Compared to children and adolescents who did not have asthma and other physical or mental illnesses, children and adolescents with asthma had higher teacher- and parent-reported psychological problems, including emotional problems, conduct problems and hyperactivity problems (Calam et al., 2005). These unwanted psychological consequences may be related to constantly being ill, having school absence and underperforming in sports resulting from asthma attacks (Vila et al., 2000; Roder et al., 2003; Milton et al., 2004). Therefore, experiencing an asthma attack or the fear of experiencing an asthma attack can be a short and a long term life stressor.

To summarise, living with asthma implies having to consider the possibility of

having asthma attacks. Asthma attacks impair breathing, and frequent asthma attacks affect physical and psychological functions. It is common for teachers to have students with asthma in a class, but there are variations in how often they have asthma attacks.

However, living with asthma does not simply involve worrying about asthma attacks. Indeed, there are ways to stop the damage from having asthma attacks. When a child or an adolescent is having an asthma attack, s/he should be calmed down and encouraged to try to identify and to remove possible asthma triggers. It is probably a good idea to stay away from people who are smoking. Meanwhile, asthma sufferers should carry a *reliever inhaler* (nicknamed “puffer” or “squirt”), and take one or two puffs of it, depending on the prescription. Although a reliever inhaler is usually safe and useful, there can be emergencies when a full asthma attack develops in a short time. Ideally it is better if other people can be aware of the young people’s asthma attacks, especially adults who are experienced with it. Some children or adolescents have not learned how to use the inhalers properly, in which case they have a spacer (or air chamber) to help them take the inhaler.

Many teachers think controlling asthma is only about using inhalers when students have asthma attacks (Williams et al., 2008). In fact, there are also ways to reduce the frequency of asthma attacks, and people whose asthma is well controlled can lead a good life at a small cost. When asthma is properly controlled, one should be able to maintain normal physical activity and normal lung function, should be almost free of chronic and troublesome symptoms, and should not require rescue medications more than two days a week (Stoloff, 2008). Therefore, to control asthma involves both *preventing both the development and the progression of asthma attacks* (GINA, 2007; NHLBI, 2007). As in many adult chronic conditions (e.g. hypertension, diabetes, etc.), controlling asthma involves multiple aspects of life modification, and therefore usually requires successful management of daily life (Wolf et al., 2002;

Madge et al., 1997). This is why these aspects are frequently referred to as “asthma management” (BTC, 2005; NHLBI, 2007).

There are many ways to classify asthma management behaviours, but they usually cover the following categories:

### *Proper medication*

People usually know that children or adolescents should use their reliever inhalers when they have an asthma attack, but not everyone knows that those who tend to have frequent or severe asthma attacks (more “severe” asthma) are prescribed with *preventer* medications. Preventers are oral or inhaled medications to be taken regularly (usually daily) to prevent asthma attacks. In a similar way to older people who take pills to control their hypertension or diabetes, the preventer medication has to be taken regularly over a period of time (usually months to years) in order to see any improvement. The most commonly used preventer is inhaled steroid (inhaled corticosteroid). Although negative perceptions towards steroids might affect attitudes towards the preventer inhaler (Orrell-Valente et al., 2007), apart from long term oral steroid use, the risk of inhaler overdose is very low, and the side effects of inhaler overdose are usually minimal.

### *Trigger Avoidance*

The less exposure to asthma triggers, the less likely one is to develop asthma symptoms, which also means less medication is needed to control asthma symptoms. Many people can identify the factors that trigger their asthma. Some of them are allergens, such as dust mite or pollens. Others are non-allergens, such as air irritants (smoke, cold air, or viruses) or some autonomic system disturbance that causes airway narrowing (physical activity, emotional disturbances). Although some people with

asthma may think these triggers are unavoidable, they are sometimes not aware of the ways that help them to avoid triggers -- clinical guidelines for asthma management are primarily focused on “what to avoid” and “what to educate.” Issues on “*how to avoid*” or “*how to educate*” are still under-addressed in clinical practice (Stoloff, 2008; Guevara et al., 2003).

### *Physical activity*

Despite the possibilities of having asthma attacks, most children and adolescents with asthma enjoy sports. Physical activity promotes heart and lung function and prevents co-morbidities (e.g. obesity) that increase asthma severity, and full participation in physical activity (at play or in organised sports) is recommended for all children and adolescents with asthma except for very extreme examples (Ram et al., 2000; NHLBI, 2007). However, many of them, their parents, and their teachers are unaware that exercise-related asthma can be fully prevented (Williams et al., 2008; Fereday et al., 2009). In fact, symptoms during physical activity can usually be prevented by having inhalers and warming-up before vigorous sports (Mickleborough et al., 2007; NHLBI, 2007).

### *Asthma status monitoring*

Children and adolescents with asthma need to live with the disease for years, and the symptoms of asthma can fluctuate day by day throughout this period. In the UK they are recommended to visit doctors at least once a year to evaluate the status of asthma and to review their medications (BTC, 2005). However, clinical visits are usually less frequent than they should be (van Gent et al., 2008). Apart from clinical visits, people with more severe asthma or more frequent asthma attacks are recommended to use a *peak flow meter* regularly or as required (Burkhart et al., 2007b). A peak flow meter is a simple device that allows patients to measure their

own lung capacity, so that a sensitive objective measure can be obtained before the awareness of subjective feelings. However, peak flow meter regimes are frequently not consistently followed (Stahlman et al., 2006).

In the latest international guidelines for asthma management at the time this thesis was written (GINA, 2007), it is stated that

*“Avoidance of unfavourable environmental conditions is usually unnecessary for patients whose asthma is controlled. For patients with asthma that is difficult to control, practical steps to take during unfavourable environmental conditions include avoiding strenuous physical activity in cold weather, low humidity, or high air pollution; avoiding smoking and smoke-filled rooms; and staying indoors in a climate-controlled environment.”*

We should recognise the danger of interpreting this opinion at health professionals’ and patients’ reciprocal convenience – health professionals generally find it more difficult (and feel less obliged) to educate patients on a healthy life style than to prescribe inhalers (Yarnall et al., 2003): “Since non-medication asthma management is only for patients whose asthma is not controlled, perhaps it can be discussed only when medication does not work.” In contrast to this perspective, the current thesis aims to consider multiple aspects of asthma management regimes as equally important, including medications and life style modifications. Therefore, taking medications is not assumed in this thesis as “the top priority” of asthma management. Instead, the thesis aimed to explore qualitatively how adults know and understand the different aspects of adolescents’ asthma management (chapter 5).

To summarise, living with asthma is about managing asthma attacks and preventing asthma attacks. This involves a range of asthma management behaviours in medication and life-style modifications, and these might not always be easy for young

adolescents. Therefore, this thesis is about how young adolescents find ways to adhere to these asthma management behaviours.

### **Adhering to asthma regimes**

Although medical regimes are prescribed to treat diseases, people frequently do not follow them. Adherence, therefore, is the extent to which a patient's behaviour coincides with medical or health advice (Haynes, 1979), or the extent to which patients adhere to their medical regimes. Not surprisingly, better adherence is associated with less overall medical cost and fewer complications, especially in chronic illnesses, such as asthma (Sokol et al., 2005a; Osterberg and Blaschke, 2005; Burkhart et al., 2007a; Sokol et al., 2005b; Lim et al., 2008). Thus it is important for health professionals to assess patients' adherence in order to evaluate the real efficacy of medical regimes. There are several conceptually overlapping terms related to adherence. In the British Guidelines on the Management of Asthma (BTC, 2005), the term *concordance* has replaced *compliance* to emphasise the nature of mutual agreement between doctors and patients, and has been increasingly used in recent studies (Bokhour et al., 2008). Compared to concordance and compliance, the term "adherence" is a neutral term and does not indicate which party makes the rules (Horne, 2006). Nonetheless, there is still a significant reliance upon patients' self-will and emphasis on *intentional behaviours* -- patients need to keep reminding and motivating themselves to maintain these adherence behaviours. In particular, patients with chronic illnesses are often asked to take medication and/or make changes to their lifestyles for a long period of time, sometimes for years or even decades. Perfect adherence (or compliance) is not always a realistic goal in practice, but this fact is sometimes not realised by health professionals (Burgess et al., 2008).

Adherence issues in child and adolescent care are a major topic in *paediatric psychology* (Roberts, 2003) -- children often find it difficult to adhere to their medical

regimes, especially when they reach adolescence (Osterberg and Blaschke, 2005; Buston and Wood, 2000). In particular, children or adolescents with asthma are required to manage their disease on a daily basis for months or even years. The chronic nature of asthma and the complexity of asthma regimes make it more challenging for them to comply. The developmental change of asthma adherence in early adolescence has been demonstrated in controller medications. In a semi-blind adherence study, 100 children and adolescents with asthma (aged 8-16) were monitored with electronic inhaler devices (on corticosteroid inhalers) without telling them how adherence was monitored. The results showed a significant negative correlation (-0.21) between age and drug adherence. The highest mean drug adherence was 56% in 8-10 years olds, followed by 44% in 11-13 years olds, and the lowest was 42% in 14-16 years olds (McQuaid et al., 2003). However, this study only concerns drug adherence, and there has been no study investigating the developmental change in other aspects of asthma management. Therefore, this was investigated in this thesis, and the results are presented in chapter 4.

### *Measuring adherence*

However, it is probably as hard to measure adherence as it is to improve it. Machine monitoring is an objective method of measuring adherence to drug prescriptions or health behaviours -- pedometers are used for physical activity, or household nicotine sensor for tobacco exposure (Womboldt et al., 2002; Schofield et al., 2007). There are also devices for preventive asthma inhalers, which record the time when inhalers were used (Le et al., 2008; McQuaid et al., 2003). However, monitoring devices are expensive, and can only be applied in very limited and controlled situations where monitor machines are available. Meanwhile, monitoring methods do not directly measure the intentional behaviour itself, and should be used cautiously when behavioural intervention is considered. Self-reported adherence, on the other hand, is simple and widely accepted in clinical studies despite the limitations

(Kyngas et al., 2000; Osterberg and Blaschke, 2005; Halterman et al., 2008; Martinez et al., 2007) -- as a subjective method, self-reported adherence is criticised as being prone to report biases, such as recall bias or social desirability bias. An alternative commonly used approach is to use a pill counting strategy, where doctors count how many pills were used by calculating the difference between the number of drugs prescribed at the last visit and the number of drugs which remains in this visit. Although it is relative free from patients' recall bias, it can only be used in adherence to medications.

These different ways to measure adherence have been investigated in many studies for patients with AIDS (acquired immunodeficiency syndrome) and their adherence to AIDS drugs. In AIDS adherence studies, it is generally admitted that self-reported adherence and pill count overestimate adherence, and machine monitoring underestimates adherence (Liu et al., 2001; Arnsten et al., 2001; Samet et al., 2001). Among self-report measures, face-to-face interview has been suggested as the most reliable way of report, followed by self-administered questionnaires and audio/computer aided interview (Bender et al., 2007; Burkhart et al., 2001). Nonetheless, the concepts of over-estimation and under-estimation only apply to situations where absolute numbers of behaviour are concerned. In many questionnaire studies, it is the relativity of behaviours (compared to others or compared to weeks ago) that matters. Therefore, reliability and validity of an instrument are of more concern in such studies (Martinez et al., 2007), and patients' self-reported adherence is generally recommended as the most feasible way to evaluate patients' asthma adherence in real clinical settings (GINA, 2007).

Meanwhile, one of the AIDS adherence studies demonstrated the discrepancy in questionnaire-based adherence measurements reported by different respondents (informants). As a result, only the self-reported adherence, but not the health providers' opinions, was correlated with clinical (virologic) outcomes (Haubrich et

al., 1999). Similar results were shown in a recent study where parent-reported child asthma adherence, but not physician-reported adherence, was correlated with child asthma outcomes (Burgess et al., 2008). The lack of correlation between health providers' opinions and clinical outcomes might be due to social desirability -- patients or parents may feel more comfortable reporting their adherence to researchers who are independent of their health care. Therefore, it is important to emphasise the independence of the research from the medical care system to minimise the effect of social desirability when we measure adherence.

In the development of autonomy in early adolescence, the choice of informants is not only between doctors and patients, but also between parents and adolescents. It becomes a major issue in questionnaire-based studies of asthma adherence. Although adolescent-reported adherence seems to be more authentic than parent-reported adherence, medication adherence has not been frequently reported by young adolescents, perhaps because of the questionable reliability and consistency of methods (Griesler et al., 2008; van Dellen et al., 2008; Burkhart et al., 2001). However, there is also evidence in one study showing that child or adolescent report are more accurate than parent report in asthma adherence (preventive medications only) of children or adolescents aged 8-18 years, using machine monitored adherence as the gold standard (Bender et al., 2007). In the study, the authors explained that the poorer accuracy of parent-reported adherence may be due to parents' limited knowledge of older children's behaviour, or to parents' tendency to provide socially desirable answers. However, the current evidence has not been sufficient to draw a conclusion. In contrast to medication adherence, studies on young adolescents' physical activity or smoking behaviour usually do not rely on parent reports (Hagger et al., 2005; Motl et al., 2005; Trost et al., 2002; Chen et al., 2006). The difference may be due to the nature of medication and life style behaviour perceived in a family, but may also be due to discrepancies between medical and educational researchers on the reliance of adolescent reports. Therefore, the validity and reliability of parent and

adolescent reports still need to be investigated in further studies.

So far several issues in asthma adherence have been reviewed. First, there is evidence showing a declining adherence to asthma medication regimes in early adolescence, but the evidence in other aspects of asthma adherence is still absent. Second, measuring or monitoring asthma adherence involves methodological choices. Compared to machine-monitoring and doctor-reported adherence, patient-reported adherence has limitations in lack of objectivity, but it is strong in its authenticity, feasibility, and applicability to most types of adherence behaviours. Meanwhile, report bias can be reduced in non-health settings and in studies focusing on individual differences (i.e. less concern on over-estimating or under-estimating actual adherence). Third, measuring or monitoring asthma adherence in early adolescence involves an additional methodological choice between parent report and adolescent report. Although there are concerns as to the reliability of adolescent report, there is also evidence supporting the value of adolescent report.

In this thesis, potential changes in adolescence as a result of developmental change will be investigated on a different range of asthma adherence behaviours. In the literature, adherence to asthma regimes is usually considered as a combination of unrelated behaviours, among which, adherence to inhaled corticosteroid regimes (preventive medication) has been the main focus of adherence study in childhood asthma (Bokhour et al., 2008; van Dellen et al., 2008). There have also been several studies which have investigated non-medical aspects of asthma management, among which smoking and physical activity are most commonly seen (Chen et al., 2007a; Williams et al., 2008; Fereday et al., 2009). In contrast to individual asthma management behaviour, a summative assessment of asthma management can provide comprehensive information on asthma adherence. For example, asthma management has been conceptualised as a multi-dimensional construct in the Family Asthma Management System Scale (FAMSS), in which asthma management of children and

adolescents (aged 7-16) was measured by a semi-structured family interview coded by the interviewers using a 36-item quantitative coding scheme (McQuaid et al., 2005). The dimensions in the coding scheme were asthma knowledge (3 items), symptom assessment (5 items), family and child response to symptoms and exacerbations (3 items each), environmental control (5 items), medication adherence (7 items), collaboration with health care provider (5 items), and balanced integration of asthma and family life (5 items). The asthma management score (FAMSS score) was calculated as the mean of all subscale mean scores. For the 115 children and adolescents in the study, FAMSS score was not associated with age, gender and race, and it was negatively correlated with concurrent asthma morbidity (McQuaid et al., 2005). To date, FAMSS is the only questionnaire in which psychometric properties have been published in the English literature concerning asthma management as a multi-dimensional construct. There have been other composite asthma management scales rated by physicians or parents in other studies, but their psychometric properties have not been documented (Logan et al., 2003; Bourdeau et al., 2007).

Although the concept of multi-dimensional disease management has not been commonly used in adolescent asthma, it has been commonly seen in studies on adolescent diabetes. There are many similarities between asthma and diabetes. In the same way as child or adolescent asthma, child or adolescent diabetes is also a chronic incurable illness involving medication (insulin injection) and life style management (healthy eating, physical activity, etc.). A consequence of poor adherence is hypoglycaemia (low blood glucose level), which is an acute life crisis. Similar to the chronic lung damage in asthma, there are long-term invisible consequences of poor adherence in diabetes – poor diabetic control in children and adolescents is related to heart attack and stroke at young ages. Compared to asthma, the literature on diabetes disease management is much richer, and therefore examples of research on diabetes will be frequently used in this thesis as the basis for knowledge of young adolescents with chronic illnesses. In diabetes, *self-care* has been a well-accepted multi-

dimensional concept of adherence, which frequently includes medication, blood glucose monitoring, diet, exercise, and (avoiding) smoking. Diabetic self-care has been used in parallel with biological outcomes (metabolic control) in many studies to evaluate the efficacy of diabetic control (Toobert et al., 2000; Dashiff et al., 2009; Berg et al., 2007; Wysocki et al., 2006).

By contrast, studies that assess multi-dimensional asthma management are scarce. Following the Family Asthma Management System Score (FAMSS) in conceptualising asthma adherence as a single and multi-dimensional construct (McQuaid et al., 2005), a new summative asthma adherence scale has been developed in this thesis. The first step of the validation process is presented in chapter 3. Unlike the FAMSS, the new adherence scale concerns asthma adherence as young adolescents' actual management behaviour, and does not include their knowledge, attitudes and feelings. Meanwhile, this adherence scale concerns the young adolescents' asthma adherence, not family asthma adherence. These features allow researchers to investigate asthma adherence as adolescent behaviour, but not adolescent cognition. Moreover, instead of conducting family interviews as in the FAMSS, this scale consists of parent-reported and adolescent-reported items, giving parents and adolescents independent opportunities to report on adolescent adherence behaviour. This non-interview measure makes it more feasible for medical and school use.

Nevertheless, the purpose of this thesis is not simply to observe changes in asthma adherence in early adolescence. Asthma adherence in early adolescence may be a potentially serious issue and indeed getting worse. However, this thesis is about the social environment of asthma adherence in early adolescence. So far the discussion has focused mainly on medical theories in asthma adherence. From a psychological point of view, on the other hand, it is relevant to ask "what in early adolescence contributes to the developmental changes in adherence behaviour in early

adolescence?” “Is adherence a medical term, a psychological term, or a social term?” These are more relevant questions in this thesis. To address these questions, the social life of young adolescents will be reviewed in the next section, and the meanings of *social environment* will be discussed.

## **2.2 Adolescent behaviour and social life**

The social life of young adolescents with asthma has been explored in a qualitative study by Ayala et al. (2006). Fifty middle school students (age 13-15) in the US participated in focus groups to discuss the challenge of asthma management during the transition from primary to middle schools. Regarding their medical regimes, all students stated that taking medicine was inconvenient or undesirable, and all students thought using peak flow meters was not necessary. When they were asked why they did not take their inhalers as prescribed, common reasons included forgetting to take medicine to school or to a friend’s house, losing inhalers, and being too lazy to be responsible.

They also talked about the challenges in their daily activities. Some students reported that teachers and coaches often accused them of faking asthma attacks, which inhibited them from reporting attacks to school staff members. Among peers, students reported that it was difficult to turn down a friend’s offer to play basketball when the pollen count was high. However many of them actively limited their activity levels, which involved knowing their own physical limits and sitting down until the episode subsided.

When asked about the changes they perceived in asthma management during the school transition to middle school, the students felt that they were gaining more autonomy and responsibility for asthma management from parents. Although the students perceived that parents maintained primary responsibility for trigger

avoidance, they were also aware that they had more control over medicine in middle school than they did in elementary school. However, having multiple teachers without a primary carer in the middle school posed problems for asthma management. Students also stated that the more stringent physical education requirements in the middle school made it more difficult to manage asthma, and caused them to experience more breathing problems.

Although this was a small-scale qualitative study, similar results have been shown in other qualitative studies at different ages in adolescence (Buston and Wood, 2000; Penza-Clyve et al., 2004). These examples have described asthma management from a young adolescent's point of view – this contrasts substantially from how asthma was described in the beginning of this chapter, where asthma management was “professionally” classified into proper medication, trigger avoidance, physical activity and asthma status monitoring, or where poor asthma adherence was connected to poor asthma control and many physical and psychological problems. Compared to that perspective, these qualitative studies describe the real-life experiences of these young adolescents. For them, managing asthma is sometimes a nuisance, not only because the behaviour itself demands extra efforts, but also because of the sacrifices they are required to make in their social life which negate the experiences of asthma management.

To people who work with young adolescents with asthma, therefore, it is relevant to understand what the social life of young adolescents is like in order to discuss how it is impacted by asthma and asthma management. Just as asthma management regimes have changed in the past decade, adolescent life in the 21<sup>st</sup> century cannot be assumed to be the same as it was previously. Therefore, this review focuses on more recent literature describing a young adolescent's life within the past 5 to 10 years (1999-2009).

## **Thinking as a young adolescent**

Many parents are surprised at what their children are capable of when they reach early adolescence. They can understand much more complicated conversations on television, and process information much more accurately and quickly than younger children (Wassenberg et al., 2007; Kail and Ferrer, 2007). The blossoming of cognitive capacity is evident, and sharply widens children's learning abilities and their perceptions of the world. As a result of cognitive development, children's ability in *perspective taking* is also expanded -- they portray what other people think or feel, and make sense of their behaviour (Piolino et al., 2007) However, being mature in perspective taking and being aware of different aspects of a context does not automatically make the world easier to understand, but the way young adolescents evaluate and judge other people does become more comprehensive. At the same time, young adolescents start to develop their moral sense towards *relativism* (Krettenauer, 2004; Hart and Carlo, 2005) – nothing is absolutely right or wrong, and the value of an action can be individually assessed through hypothesising the intentions and the impacts of it. Therefore, actions against the law might not be morally wrong, and there may be evil actions without breaking the law (Christie and Viner, 2005). In short, early adolescence is a period of blossoming cognitive capacity, which enables them to view things from different perspectives. More importantly, as they learn to appreciate different perspectives, they also learn to understand and respect individual differences. This is a milestone of the socialisation process, and development of this feature of adolescent thinking may be relevant to adolescent behaviour and decision-making (discussed later).

### *The development of self*

As young adolescents are conceiving what other people are thinking and making sense of the world, it is hard for them not to think about themselves: "Who am I?"

Young adolescents start to develop a more stable and consistent *self*, as demonstrated by latest research efforts with reliability-related methodological approaches. Through this approach, a more reliable self-description seems to indicate a more consistent self. For example, in an interview study using test-retest reliability methods, 102 participants of different ages (8, 12, 16 and 20) were interviewed twice (2 weeks apart) to describe their life events. The interviews were coded (quantified) into different types of life events, temporal sequences of these life events, and interviewees' causal inference between events and their personality (i.e. how these life events changed them). Indicators of consistencies were calculated by examining correlations of participants' report between the two interviews. Not surprisingly, older participants were more consistent between two interviews in all consistency indicators (Habermas and de Silveira, 2008). Conceiving self-described life events (or self-narratives) as one aspect of self, this study seems to suggest a more stable self in late adolescence than in early adolescence. This stabilising process was replicated in another study which compared younger adults (age 17-35) and older adults (age 65-85), suggesting an ongoing formation of narrative self across the life time (McLean, 2008).

Internal consistencies of psychological instruments, another useful indicator of instrument reliability, have also been used as tools to describe consistency of self. For example, in a web-based large series (n=230,047) of self-reported "big-five" personality, the internal consistency of self-report personality within personality domains was compared among participants between 10 and 20 years old. The results showed that internal consistencies increased with age within all personality domains (Soto and John, 2008). Moreover, the study also demonstrated that the degree of differentiation *between* personality domains increased with age. Therefore, when adolescents become older, their self-concept is not only more stable but also more diversified.

Indeed, the diversification is not only seen in their personalities, but also seen in the many ways they describe themselves. Compared to earlier childhood, adolescents like to describe themselves in more abstract and psychological ways, for example, “I am sentimental,” “I am such a drama queen” (Habermas and de Silveira, 2008). They also like to portray themselves with their competencies by social comparison, “I am the best singer of my class,” “I am not as sporty as others” (Harter, 1999b). Gradually, they start to differentiate among multiple aspects of self, “I am generally good in school work but not so good in maths” (academic self), “I am good-looking but not so popular” (physical self). Interestingly, they may also be confused or not aware of their different selves in front of friends and in front of parents, and this turmoil can continue at least until middle adolescence (14-16 years old) (Harter, 1999b). This may explain why many of them are involved in smoking, fighting, or other risk-taking behaviour – they may see themselves as “bullet proof” or “immortal,” even when the risks are well-perceived by their rational selves at the same time (Christie and Viner, 2005).

### *Self-esteem*

In addition to differentiation of self, researchers are also interested in adolescents’ global evaluation of self, or self-esteem. Gaining self-esteem is very important to a young adolescent, and a young adolescent who has poor self-esteem can be more easily involved in aggression, antisocial behaviour and delinquency (Donnellan et al., 2005; DuBois and Silverthorn, 2004b). Therefore, it is not sufficient only to know “who I am” or “what I am capable of.” It is also an important part of a young adolescent’s life to have self-esteem. Self-esteem can be gained from many aspects of self, but some aspects of life seem more important to young adolescents nowadays, at least in Western culture – they seek to have good school achievements (academic self), good sports performance (physical self), good appearance (physical appearance self), and good popularity (social self) (Stone et al., 2008; Harter, 1999a;

Marsh, 1989; Prinstein and La Greca, 2002).

Self-concept in later adolescence becomes so diversified (Habermas and de Silveira, 2008) that comparing a global assessment between younger and older adolescents becomes difficult. This is well-demonstrated in an early study where 12,266 children and adolescents (age 7-22) in Australia completed self-description questionnaires (SDQ1, 2 and 3 for different ages). This study demonstrated a U-shape development of global concept, which decreased in early adolescence, troughed at mid-adolescence, and increased in late adolescence (Marsh, 1989). However, although a broad age range was included in this study, it is difficult to interpret results from a cross-sectional study where participants of different ages completed different questionnaires. By contrast, most recent studies on self-esteem tend to be smaller, and cover a shorter age span. In general, there is still no strong evidence to draw conclusions on the developmental change in self-esteem across adolescence (DuBois et al., 2002; Montague et al., 2008; Way et al., 2007). More studies are required to confirm this finding in the 21<sup>st</sup> century.

So far the theories briefly reviewed above have described how children's minds grow into adolescence, and how social and cognitive development leads to the formation of self. The expanding cognition allows young adolescents to respect different perspectives of others, and to develop different perspectives of self. These may all affect adolescents' behaviour, and may affect the decision of disease management among adolescents with asthma. However, behaviour is not only about children's psychological development, but also about the interaction between psychological development and environmental stimulation. To understand the behaviour of a young adolescent with asthma, therefore, it is also relevant to review the environment of early adolescence.

## Human behaviour and the social environment

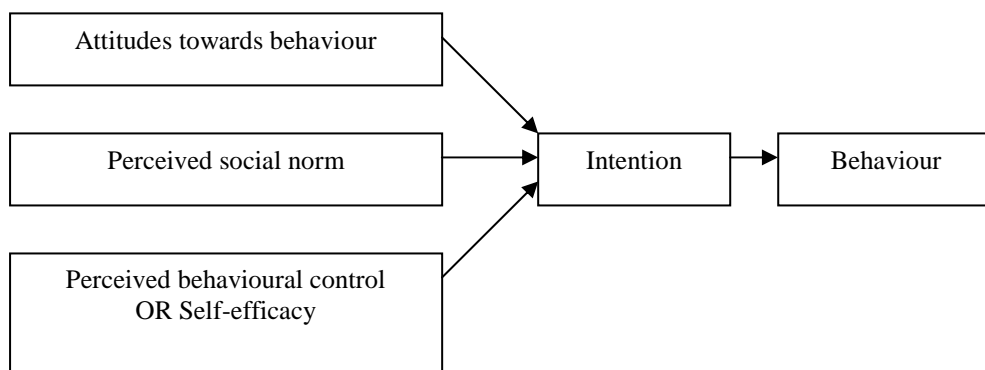
When an adolescent has an asthma attack in a football game and finds it difficult to breathe, he may decide to leave the game to take a puff of his reliever inhaler. This decision is probably based on several beliefs: he believes that the inhaler will relieve his breathing difficulties, and he also believes that it is fairly easy for him to take the inhalers. These beliefs are again based on other knowledge or experiences: he may remember an earlier occasion where he was so short of breath that he was sent to the hospital; this makes him think that he should probably use the inhaler sooner this time. He may also realise that it will be half-time break in a few minutes, and he will be able to have a rest and use the inhaler without disrupting the game. The knowledge or experiences which influence his beliefs about using the inhaler, furthermore, are also subject to the influence of higher-order knowledge or personal characteristics, such as his enthusiasm for playing football, his compliance in bringing the inhalers with him, or his ability to use the inhaler accurately.

### *Behavioural psychology*

These psychological factors of human behaviour, including beliefs, knowledge, attitudes or other personal characteristics, have been mapped into behavioural theories by behavioural psychologists. For example, according to the theory of Planned Behaviour (Ajzen, 1991), human behaviour is influenced by *attitudes towards behaviour*, perceived attitudes of significant others (*perceived social norms*) and perceived confidence to enact the behaviour (*perceived behavioural control*) (figure 2-1). Another widely used concept similar to perceived behavioural control is (*perceived*) *self-efficacy* in *Social Cognitive Theory* (Bandura, 1997; Bandura, 2001), or the belief that one is capable of performing in a certain manner to attain certain goals. In other words, whether or not the adolescent takes the inhaler is influenced by his general attitudes towards the inhaler (attitudes towards behaviour),

his perceptions of other people’s attitudes to the use of inhalers (perceived social norms) and his confidence in using the inhaler (perceived social norms or self-efficacy). Applications of these behavioural theories have had a major influence on research and clinical practices to moderate health-related behaviour. In the Lifestyle Education for Activity (LEAP) study (Dishman et al., 2004), for example, 24 classes with 2087 adolescent girls in the US were randomly assigned to two physical activity promotion groups. Girls in the intervention group received a school-based, 2 year multi-component intervention which emphasised enhancement of self-efficacy and development of behavioural skills (e.g. goal setting, time management). Compared to the girls in the control group who participated in normal physical activity classes, the girls who received the intervention had a significantly higher level of physical activity and a higher level of self-efficacy. The authors also demonstrated that the increase in physical activity was partially explained by the increase in self-efficacy. In other words, through the intervention, the self-efficacy of physical activity was enhanced, which encouraged girls to increase physical activity.

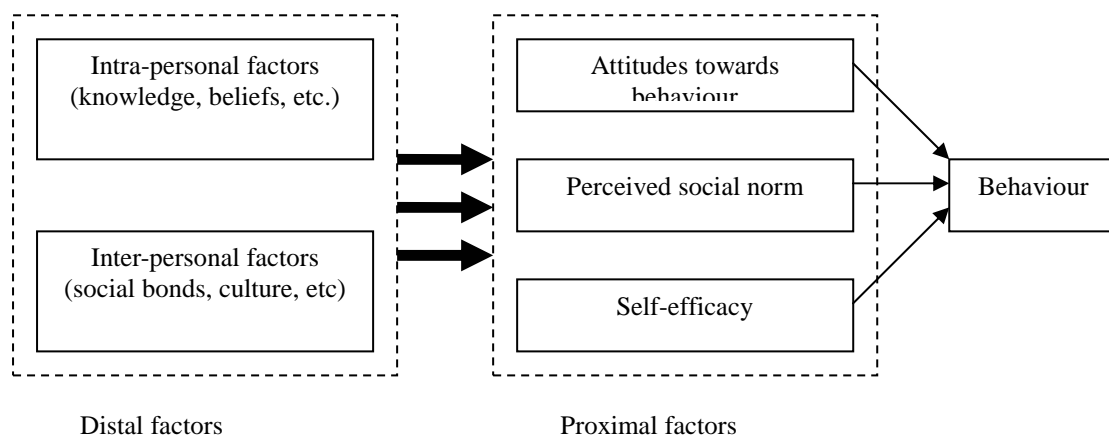
Figure 2-1 Theory of planned behaviour, and example of theories in behavioural psychology



The LEAP study is not the only example of success in behaviourally driven adolescent health studies. In a systematic review of 87 adolescent studies carried out between 1995 and 2003 in four adolescent health-related behaviours, Peters et al examined the behaviour-specific and non-specific psychological determinants of the health-related behaviours (Peters et al., 2009). As expected, among all the

psychological variables, attitudes, social norms and self-efficacy were the most consistent factors associated with tobacco smoking, alcohol use, nutrition and/or safe sex. Confirming evidence in the current literature on health promotion, the authors argued that these were the most *proximal factors* to behaviour (figure 2-2). However, it does not mean that other (distal) factors are less important than the proximal factors. Instead, in the study Peters et al. proposed that the three proximal factors (attitudes, self-efficacy and perceived social norms) were influenced by distal factors, including other intra-personal factors (e.g. knowledge, beliefs, etc.) and inter-personal factors (social bonds, cultural factors, etc.). In other words, it is possible to modify the three proximal factors by altering the distal factors in order to promote desirable behaviour.

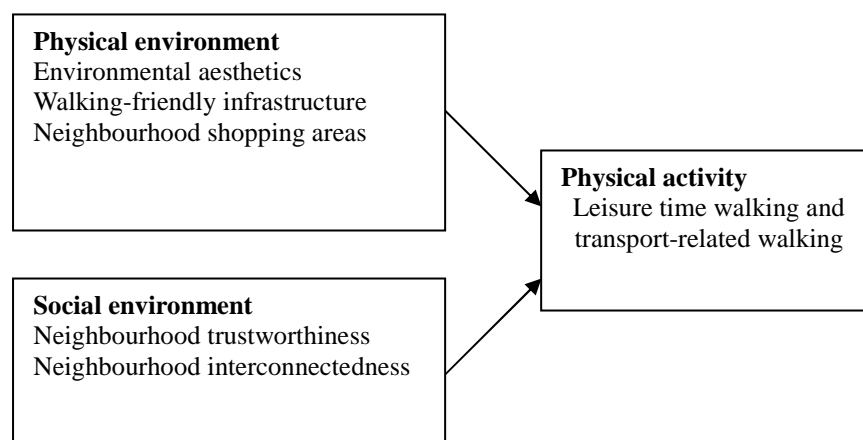
Figure 2-2 Extensive model to explain human behaviour (Peters et al., 2009)



This is not the first time that behavioural health psychologists have introduced the notion of an interaction between intra- and inter-personal factors of human behaviour. As early as the 1970s, *human behavioural ecologists* began to study human behaviour as an adaptive reaction to the environment with the constraints of human biology (Winterhalder and Smith, 2000). Soon afterwards, the notion of the *social environment* was first used in epidemiology as a term in contrast to the *physical environment* in explaining human behaviour within social contexts (Cassel, 1976). Building social and physical environmental factors onto the existing behavioural

theories opened up alternative possible targets to moderate health-related behaviour. The prototypical social-physical environmental categories are most widely used in studies that concern physical inactivity of modern life. In a longitudinal study carried out in Australia (Cleland et al., 2008), for example, the time mothers spent in leisure time walking and transport-related walking (as a way of daily physical activity) was predicted by previous self-reported physical and social environmental indicators. Significant physical environmental indicators were environmental aesthetics, walking-friendly infrastructure and neighbourhood shopping areas, and significant social environmental indicators were measured with neighbourhood trustworthiness and interconnectedness (figure 2-3). Using similar indicators, recent research has been carried out concerning the connection between the physical and social environment. In another large-scale Australian study (Cerin et al., 2009), for example, similar physical and social environment indicators were used, and cross-sectional data suggested that poor environmental aesthetics and walking-unfriendly infrastructure were associated with lower socioeconomic status. Therefore, it is not surprising that the physical environment and the social environment are often related in the broad sense of *social ecological* (or *contextual*) *model of behaviour* (McLeory et al., 1988; Sorensen et al., 2003; Stokols, 1992).

Figure 2-3 Social and physical environment of physical activity (Cleland et al., 2008)



So far several important issues in behavioural psychology have been discussed. In general, these behavioural theories recognise the role of human intentions in enacting behaviour, but at the same time emphasise the interaction between the intentions and the environment which shapes human behaviour. This thesis specifically concerns the social environment which influences young adolescents' asthma management behaviour. Although there is no agreed definition of the social environment in the health literature, the studies concerning social environment usually involve one or more overlapping concepts, which include specific social support, socioeconomic status, and social capital. These were the three aspects of the social environment that help to develop the hypotheses of this thesis.

#### *Specific social support*

Not surprisingly, *specific social support* is one of the most widely investigated indicators in the social environment. It is usually defined as the activities or behaviour of other people, organizations or society that directly support the particular behaviour. When it is self-reported, specific social support is indistinguishable from perceived social norms, which (as mentioned earlier) is one of the proximal predictors of health behaviours in adolescence (Peters et al., 2009). Another aspect of specific social support focuses on the radical influence of society. For example, in a large-scale (n=4919) survey in the US, seeing tobacco smoking in films was associated with smoking attempts among adolescents aged 9-15 (Sargent et al., 2001). After 13-26 months of follow-up, parental restriction of R-rated movie and seeing less tobacco smoking in films predicted a lower rate of adolescent smoking initiation (Sargent et al., 2004; Dalton et al., 2003). In some ways, the images or advertisements in the films created a tobacco-approving social environment which encouraged young adolescents to smoke. Therefore, specific social support can be the activities of other people in relation to the behaviour, and can also be the activities of society in relation to the behaviour.

### *Socioeconomic status*

Other researchers have investigated the social environment by studying the impact of socioeconomic status on human behaviour. However, this impact is never straightforward. In a systematic review, 162 studies were examined to investigate associations between socioeconomic status and cigarette smoking, alcohol consumption, marijuana use, diet, and physical activity in adolescents aged between 10 and 21 years old (Hanson and Chen, 2007). The results varied with the behaviours. Low socioeconomic status was associated with less healthy diets, less physical activity, and greater cigarette smoking, but there was no clear pattern of associations between socioeconomic status and alcohol consumption or marijuana use. Variability in the impact of socioeconomic status may also exist across different socio-cultural contexts. In the Health Behaviour in School-aged Children study (HBSC), students aged 11-15 in 32 countries reported their levels of physical activity (Borraccino et al., 2009). A higher family socioeconomic status was associated with higher level of physical activity in 25 countries, but this association was not seen in 7 other countries. Therefore, understanding the complex effects of socioeconomic status on health behaviour may help policymakers to address health inequalities in the social environment, but the effect of socioeconomic status “comes as a package” – in contrast to specific social support for a behaviour, the effect of socioeconomic status is not straightforward. Higher socioeconomic status does not necessarily predict all healthy behaviours, and it is not possible to explain behaviour as a direct result of high or low socioeconomic status. There is still great variability which has not been taken into account.

### *Social capital*

Compared to specific social support and socioeconomic status, *social capital* is a relatively new but growing concept of the social environment used in social and

health research. Social capital usually refers to the existence of community networks, civic engagement, civic identity, reciprocity, and trust (Campbell et al., 1999; Putnam, 2000; Kushner and Sterk, 2005). In essence, social capital implies social cohesion or interconnectedness. Similar to socioeconomic status (and dissimilar to specific social support), social capital does not have a straightforward impact on a specific behaviour, and studies in social capital and health behaviour usually provide results that vary across different contexts. For example, the effect of social capital varies with behaviour of interest -- in a community HIV-related health behaviour study in Namibia, social capital was measured by a measure of *group centrality* (the degree to which the person is socially connected to the centre of social network). Although high group centrality among households was associated with higher HIV-related health service use, it was also associated with more negative attitudes towards monogamy and condom use (Smith and Rimal, 2009). The effect of social capital may also vary with sub-groups of interest -- in a longitudinal study of workplace smoking in Finland (Finnish Public Sector Study), high social trust and interconnectedness predicted smoking cessation in 2-4 years of follow-up only among groups of participants with high socioeconomic status, but not among groups of participants with middle and lower socioeconomic status (Kouvonen et al., 2008). Finally, the effect of social capital can also vary with aspects within social capital -- in Taiwan, adult smoking and drinking behaviour were investigated with social capital indicators across both genders. Among 3713 participants living in 204 neighbourhoods, social participation, social trust and neighbourhood closeness were used as social capital indicators. As a result, social participation was positively associated with drinking behaviour in both genders. Stronger effects of social trust on smoking were found for women than for men, and stronger effects of neighbourhood closeness on drinking were found for women than for men (Chuang and Chuang, 2008). Therefore, social capital seems to describe some aspects of the quality of the social environment, but the complex impact of social capital on the health behaviour of individuals still requires further studies to clarify.

TABLE 2-1 three aspects of the social environment discussed in this thesis

	Definitions	Example	Context-dependency
Specific social support	Activities of others or society specifically related to the behaviour	Helping or encouraging adolescents to take preventive inhalers	Activities are specific to the context
Socioeconomic status	Social standing	Education, income, etc.	Effects depend on the context
Social capital	Social cohesion and interconnectedness	Neighbourhood trustworthiness	Effects depend on the context

Specific social support, social capital and socioeconomic status represent different aspects of the social environment. A common feature of them is context-dependency. Although the effect of specific social support on behaviour is relatively straightforward, it has to be defined in relation to the relevant context. For example, this thesis concerns young adolescents' asthma management, and therefore the asthma management-specific social support is the support from others specifically towards asthma management. On the other hand, social capital and socioeconomic status are less limited to the relevant context, but the effect of these two concepts are complex and context-dependent. For example, the effect of social capital on behaviour may be different between children and adults, or between asthma management behaviour and aggressive behaviour.

The context-dependency of the social environment is of great concern in this thesis. Since this thesis focuses on the social environment of asthma management in early adolescence, it is not possible to investigate the social environment of asthma adherence in early adolescence without knowing about the social life of a young adolescent. More importantly, it is relevant to know how the behaviour of young adolescents is impacted by their social life. In the following section, early adolescent life with parents, with teachers and with peers will be discussed. By reviewing the literature on this topic, a clearer hypothesis about *how young adolescents' asthma management behaviour is impacted by the social environment* can gradually be

shaped.

### **Social life with parents: becoming independent**

In a family, children are encouraged to be more independent when they reach adolescence. This may mean that parental authority is weaker in adolescence, but this does not mean that all adolescents have the same family experiences when they become independent. In a large scale survey in the US, 1472 African American or European American families with young adolescents were followed from age 13 to 19. Compared to younger years, adolescents at the older age had more negative identification of their parents (i.e. parents are not as perfect as they thought), and they were more dominant in decision making. However, there were significant gender and ethnic differences -- European Americans tended to have more adolescent-dominant decision making styles in the family than African Americans, and *male* European American adolescents had significantly lower parental identifications than other adolescents. Meanwhile, although the frequency of family conflicts did not significantly change with age in the entire sample, the age trend was significant among African Americans -- compared to early and late adolescence, there was a transient decrease of family conflicts in middle adolescence (age 15-17) among African American adolescents, but not among European Americans (Gutman and Eccles, 2007). Therefore, it is clear from this study that adolescents become more dominant in decision making, but there are some gender, ethnicity, and time variations along this trajectory.

This is also consistent with another longitudinal study where 1313 Dutch young (aged 12) and middle adolescents (aged 15) reported their perceived family relationships over four years. Although the adolescents also perceived that parental dominance decreased year by year, they reported that the level of family conflicts was higher during middle adolescence (De Goede et al., 2009). Adolescents' perceptions

of family support were also investigated in this study. Boys and girls reported that family support declined from early to middle adolescence. Girls reported that family support increased from middle to late adolescence, but boys reported a stabilised level of support in this period. Consistent with the previous study (Gutman and Eccles, 2007), this study supports the finding that adolescents become more dominant (or less parent-dependent) in decision making, but the two studies both indicated a great inter-individual variation in adolescents' family experiences and their time trajectories when they become independent. Meanwhile, this study seems to further suggest that young people in early adolescence become more dominant in decision making, but at the same time they perceive less family support at home.

Apart from the variations with time and people, this shift of dominance in decision making in young adolescence may also vary with life domains. This was studied among a young population in a longitudinal study in Chile, in which 568 early adolescents (aged 11-14) were followed for 4 years. As adolescents grow older, they perceive less parental legitimacy to set rules and perceive themselves less obliged to obey their parents in case of parent-adolescent disagreement; this change was more prominent in early adolescence (age 11-14) than middle adolescence (age 15-18). However, when different domains of issues were analysed separately, the decline of perceived parental legitimacy and adolescent obligation to obey was only significant in personal domains (choice of friends, what you wear, or use of time and money), but not in prudential domains (smoking, alcohol, or drug use), parental expectation (homework, school performance and time on telephone), and opposite-sex relationships (Darling et al., 2008). Therefore, there is not only an *inter-individual* variation in adolescents' family experiences, but this domain-specific approach also helps to describe an *intra-individual variation* in different domains of adolescent life.

*Family environment – parental involvement and family warmth*

Therefore, although all adolescents seem to become more independent over time,

there are inter-individual and intra-individual variations in their family experiences, which may affect academic, behavioural, or psychological outcomes. Family experiences in adolescence have been approached in the psychological literature via several dimensions, among which *parental involvement* represents how much life of adolescents was shared with parents. In general, young adolescents whose parents are more involved and more conscientious in their life have higher academic achievement and less behavioural problems (Heaven and Ciarrochi, 2008); also, parental supervision prevents young adolescents from the adverse effects of antisocial friends (Laird et al., 2008; Adams et al., 2000). Among 1173 young Dutch adolescents (10-14 years old), when the effect of adolescent-reported family communication and trust was controlled for, secrecy from parents predicted unfavourable psychological outcomes in the next year, including lower self-esteem, lower self-control, and higher self-reported depression, stress, aggression and delinquency (Frijns et al., 2005). The authors pointed out the fact that adolescents who kept more secrets from parents still felt that they lost self-control in the following year, which indicated that parental involvement and adolescent self-control may not be a zero-sum relationship. Therefore, cumulative evidence seems to suggest a general benefit from family life-sharing (or parental involvement) in adolescence.

The benefits of parental involvement independent of family communication and trust do not hamper the importance of family communication and trust in adolescents' family life. In fact, family communication and trust are the *styles* of parent-adolescent interactions, which represent another aspect of young adolescents' family environment that is related to adolescent social outcomes. A supportive family environment seems to be related to a warm and less-conflicted style of parent-adolescent relationship. For example, in a semi-structured interview study carried out in Israel where 203 young adolescents (aged 9-11) reported their perceived relationships with mothers, the adolescents who perceived their mothers as warm and benign had fewer teacher-reported behavioural problems (Waniel et al., 2008). A less-

conflicted family relationship also predicts future outcomes. In the Springfield Child Development Project, 440 American families with children and adolescents aged 7-13 were followed for six years. Families who reported themselves as more cohesive and less conflicted were associated with decreasing aggression behaviour from age 7 to 19, and the effect was more prominent among children who were more aggressive at age 7 (Andreas and Watson, 2009). Therefore, being warm and less-conflicted seems to be an important feature of a supportive family environment.

Since family conflicts are usually conceived as a negative experience in adolescence in the literature, the way a family deals with family conflicts is an important factor of family functioning. A cross-sectional study in the Netherlands aimed to investigate whether the relationship between family conflicts and adolescent psychological adjustment was moderated by family conflict coping styles. The coping of family conflicts was categorised into five styles: positive problem solving, conflict engagement, withdrawal (avoiding the problem and becoming distant), compliance, and exit (ending all contact without solving the problem). Using clustering analysis, 1313 early and middle adolescents were clustered into five groups based on their self-reported frequencies of the five conflict styles. The study confirmed other literature in that family conflict frequencies were associated with internalising and externalising problems in early and middle adolescence. Interestingly, when withdrawal was the only strategy used to resolve family conflicts, conflict frequency was more strongly related to externalising problems. On the other hand, when withdrawal was used in combination with other styles, conflict frequency was more strongly related to internalising problems. Finally, the positive conflict types, in which positive problem solving was the main strategy, were associated with less psychological problems (Branje et al., 2009). Therefore, a supportive family environment is not only associated with reduced family conflicts, but also related to a positive problem-solving coping style (but not a withdrawal style) in family disagreement. In other words, effective communication in family disagreement is as important as avoidance

of confrontations. A warm and less-conflicted family relationship may be associated with good adolescent outcomes, but it is effective communication in a family that supports a warm and less-conflicted family environment.

The observational studies mentioned above only demonstrate the importance of parental involvement and a warm (i.e. less conflicting and effectively communicating) parent-adolescent interaction. By contrast, there have been many successful interventions which have shown the broad benefits of parenting skills for adolescence. As expected, these skills usually involve active engagement in parent-adolescent interaction and communication skills that help to deal with family disagreement. In the Preparing for the Drug-Free Years Study (PDFY), for example, 429 parents of 11 year-old adolescents attended five sessions of parenting skill training. This intervention provided opportunities for proactive involvement in the family, including participation in adolescent activities, problem-solving, and positive interaction with other family members. There were also behavioural skills (e.g., positive or negative reinforcement) for parents to encourage appropriate and discourage inappropriate behaviours. After a 5-year follow up, adolescents and those whose parents received the intervention reported fewer depressive symptoms (Mason et al., 2007). Different from Mason et al's study which targets the general population, other interventions have also been shown to help a smaller number of adolescents with high risks using more intensive approaches. In Adolescent Transition Programs, for example, families of 106 high-risk adolescents (age 11) received a family-oriented treatment, which is based on motivational interviewing techniques designed to enhance family engagement and to improve composite parenting skills (Dishion and Kavanagh, 2003). Compared to the adolescents in the comparison group, the adolescents in the intervention group not only had fewer depressive symptoms, but also had less conduct problems and less substance use across the adolescent period (Dishion et al., 2002; Connell and Dishion, 2008). The results of these interventions suggest that parents are able to create a warm and supportive family environment that helps to prevent

behavioural problems in adolescence by establishing effective communication with adolescents in family disagreement.

So far the discussion has established two important aspects of family environment research in the literature. Firstly, the shift of decision making dominance, or becoming independent, is a hallmark of adolescence. However, there is a great variety of family experiences along the process of becoming independent. Secondly, some experiences in the family environment in early adolescence seem to be superior to others in predicting favourable social outcomes in later years, among which parental involvement and a warm family environment have both been supported by observational and interventional studies. Therefore, adolescents received benefits from parents not only via their engagement in adolescent activities, but also via the way of family communication, trust and interconnectedness that create a warm family environment. Therefore, when we see the family environment as an important dimension of the social environment in early adolescence, parental involvement and family warmth are also characteristics in family relationships or *social capital* in a family that have an impact on adolescent social life.

A third aspect of family environment research will be discussed below. Since adolescents are developing independence and learning to make their own decisions, the third aspect of the family environment questions how parents maintain a high level of involvement and communication when adolescents develop independence. Many studies concerning this question discuss the development of *autonomy* in adolescence.

#### *Family environment – Parental autonomy support*

Autonomy is self-determination or self-regulation. It is helpful to understand autonomy by knowing its antonym, *heteronomy*, or regulation controlled by others or

by the environment (Ryan and Deci, 2006). Therefore, having more autonomy implies that one's life is more controlled by self, and not by others or the environment. Not surprisingly, the core concept of parental autonomy support in adolescence is allowing adolescents to make decisions and respecting adolescents' decisions. Similar to parental involvement and family warmth, parental autonomy support has also been referred to as a positive characteristic in family relationships, and has been associated with better school performance, social acceptance, and psychological adjustment in adolescence (Soenens and Vansteenkiste, 2005; Allen et al., 2006). Research studies have also shown that the favourable outcomes related to parental autonomy support were mediated via adolescents' sense of autonomy in taking parental advice (Knafo and Assor, 2007; Soenens and Vansteenkiste, 2005). In other words, parental autonomy support facilitates adolescents to feel that they can control their lives, and this sense of control is related to academic, social, and psychological outcomes. However, it is important to point out that most research focuses on middle to late adolescents. More studies are required to confirm the effects of autonomy support in early adolescence.

Research in parental control provides evidence of family autonomy support from another angle. In a cross-sectional study, degrees of parental influence, family warmth (family trust and communication) and parental psychological control were reported by parents and adolescents (age=13, n=176). Family warmth and parental psychological control were also observed in video-taped tasks. Interestingly, adolescent-perceived parental influence was related to adolescent-reported and observed family warmth, but not related to parent-reported family warmth. On the other hand, parent-perceived parental influence was related to observed parental psychological control, but not to family warmth (McElhaney et al., 2008b). In short, parents may perceive their psychological control as the way they influence adolescents, but adolescents seem to perceive family communication and trust as the way they were influenced by parents. In other words, parental autonomy support may be perceived by parents as a way of

losing influence.

Indeed, the idea of maintaining a high level of parental involvement and family warmth when adolescents learn to make their own decisions is usually followed by a question mark. In the literature of the past decade (2000-2009), however, there are not many studies explicitly comparing parental involvement and autonomy support in the family environment, and the results are far from consistent. For example, in a cross-sectional study in the US, parental supervision, parental autonomy support and family warmth were all associated with better psychological adjustment and life satisfaction among 1201 students aged 11-19 (Suldo and Huebner, 2004). However, this may not be supported where more specific outcomes are concerned. In another study where 1212 Belgian adolescents (aged 14-18) and parents completed questionnaires, the researchers investigated the relationships between parent support and adolescent fear of crime. Parent support was measured in four domains, including parental supervision, parental encouragement of adolescent social activities, autonomy (allowing adolescents to make decisions) and freedom (free time and time without supervision). This study suggested that the level of parental supervision was associated with more fears of crime among adolescents; parental encouragement of adolescent social activities was associated with lower levels of fear among girls, and parents who allowed adolescents to make decisions (autonomy) were associated with lower levels of fear among boys (De Groof, 2008). Compared to the first study where all aspects of parent support predicted psychological adjustment and life satisfaction, this study suggests contradictory effects of parental involvement and autonomy support on adolescents' fear of crime. It is not possible to draw a conclusion based on the small amount of current literature, but it is also not surprising to see this controversy – if parental involvement, family warmth and parental autonomy support describe the social capital of a family environment, they should be expected to have context-dependent effects. Nevertheless, most research in this field has been limited to observational studies. More intervention studies are required in the future to

explore the benefits of parental autonomy support for adolescents and the ways to support autonomy in adolescence.

TABLE 2-2 three important dimensions of the family environment discussed in this thesis

	Definitions/meanings
Parental involvement	Parent-adolescent life sharing
Family warmth	Effective communication and reducing family conflicts
Parental autonomy support	Allowing and respecting adolescent decision-making

In this section the family life of a young adolescent is reviewed. At this age, young adolescents start to become more independent and learn to make their own decisions. During this developmental process, there is a great variety of inter-individual and intra-individual differences in their family environment. Meanwhile, family environment is a multi-dimensional concept, and psychological studies have pointed out the benefits of parental involvement and a warm family environment in academic, behavioural and psychological outcomes. A third dimension of family environment, parental autonomy support, has also been associated with some favourable outcomes in middle and late adolescence. However, the literature has not provided consistent evidence in the way parents maintain high level of involvement and family warmth while they provide autonomy support. Nevertheless, parental involvement, family warmth and parental autonomy support are three important dimensions of the family environment that bring impacts in adolescents' social lives. As this thesis focuses on the social environment of asthma adherence, these may also be the important dimensions of the family environment that have an impact on adolescents' asthma management.

### **Social life with teachers in school transition**

Changes in the family environment for young adolescents such as greater independence are usually slow and general. Compared to the family environment, change in the school environment is faster and more fundamental. Young adolescents

are not only at the transition from childhood to adolescence, but also at the transition from primary school to secondary school. Ninety-two percent of students in the UK attend state mainstream schools (DCSF, 2007; Taylor et al., 2005). In a typical mainstream state school system in the UK, students move from primary school to secondary school in year 7 (age 11-12); this structure is similar now to most developed and developing countries of the world. Compared to life in primary schools, the organisation of secondary schools means that students have different classmates and different teachers in different subjects, and their school curricula become more specialised and optional, making a more diversified student body. As this thesis considers the social environment of asthma adherence in early adolescence, the impact of the school environment on adolescent social life can never be left out of discussion.

Nevertheless, there have not been many large-scale studies that have investigated students' school experiences specifically during this school transition. By following 1451 adolescents in the US from grade 6 to 8 (age 12-14) during the school transition, a study carried out by Way et al. (2007) found that adolescent-perceived school climate declined over the three years -- not only a decline in general teacher support and general peer support, but also a decline in student decision making and clarity/consistency in school rules. In other words, young adolescents did not feel encouraged to make decisions in secondary schools, and they felt less connected with teachers and peers. These changes were also accompanied by decreased self-esteem, increased behavioural problems and increased depressive symptoms reported by adolescents (Way et al., 2007). A negative impact of school transition was also demonstrated at the school transition from middle school to senior high school in the US educational system (Benner and Graham, 2009). Therefore, evidence from these observation studies seems to suggest a life stress during school transition.

### *Teachers' knowledge of adolescent behaviour*

Parents are the primary source of adult-adolescent relationships at home, whilst teachers seem to play the parents' role at school. Although many studies have investigated the effects of teacher support on adolescent outcomes, there have been surprisingly few studies which describe the characteristics of teacher-adolescent relationships in early adolescence over the past decade. This topic seems to be investigated more in adolescent bullying or victimisation than in other adolescent behaviour. For example, teacher-reported and adolescent-reported bullying and victimization were compared (aged 12-13, n=1442) in the US, and teacher report and adolescent report were only mildly agreed ( $\kappa=0.12-0.13$ ). Teachers identified more bullies and bullies-and-victims than adolescents did through self-report, while adolescents perceived themselves as victims more than teachers did. To further investigate how teachers perceived students as bullies or victims, the study found that teacher-reported bullies or victims were associated with the frequencies of teacher-reported student acting-out, moodiness (victims only) and referrals, but not with child-reported anxiety, depression, and anger (Totura et al., 2009). Therefore, the study seems to suggest that teachers in secondary schools may view students as bullies more than students perceived themselves, and this view may not connect closely to students' psychological adjustment.

Still related to adolescent bullying and victimisation, a different type of study describes teachers' views of adolescent behaviour by comparing teachers' views with other students' (peers') report. In a study carried out in Estonia, adolescent victimisation and aggression was reported by self, same-sex peers, opposite-sex peers and teachers at age 11 and 13 (n=257). The results at age 11 showed relatively low correlations between self and other reports, compared to the correlations between reports from others (same-sex peers, opposite-sex peers and teachers). By contrast, at age 13, relatively high correlations were seen among all self reports and peer reports,

though the correlation was low between teacher report and self report among boys (but not among girls) (Peets and Kikas, 2006). Although this sample may not be representative of a more general population, the study also suggests that compared to peers, there is lack of connection between teacher-reported and self-reported victims or bullies in early adolescence.

Since the teacher-adolescent relationship is also a type of adult-adolescent relationship, recent studies also compared teachers' knowledge and parents' knowledge of adolescent behaviour. For example, among 2230 adolescents at age 11 in the Netherlands, teacher-reported adolescent prosocial and antisocial behaviours were only mildly correlated with parent report (0.10-0.15 for prosocial behaviour, and 0.29-0.33 for antisocial behaviour). The study also demonstrated that teacher-reported behaviour was associated with adolescent academic performance and peer relationships, while parent-reported behaviour was associated with parent-perceived difficulty to control the adolescent (effortful control) (Veenstra et al., 2008). In this study, adolescents' self report was not investigated, and it was not possible to know how well the reported prosocial and antisocial behaviours were connected to adolescent psychological adjustment. However, this study supports the suggestion that teachers provide an adult aspect of adolescent behaviour alternative to parent aspects, and therefore they are not simply parent surrogates in school.

So far the discussion has reviewed several aspects of adolescent school life in the current literature. Firstly, school transition may be a life stress to young adolescents. They seem to perceive less teacher support and feel less autonomy in secondary school. Secondly, teachers seem to become less psychologically connected with students in early adolescence. Finally, although teachers and parents are both adults, they have different perspectives in observing adolescent behaviour. To recall the discussion on the family environment, it seems true that adolescents share less information with adults (parents and teachers), but they receive (or perceive) more

autonomy support from their parents than from their teachers, although the current evidence has not been sufficient to confirm or generalise this statement. More studies are required to understand adolescent experiences at the time of school transition; nevertheless, it is clear that teachers represent an important aspect of the social environment in young adolescents' social lives.

### *Teacher effect on adolescent outcomes – compared to parent effect*

Not surprisingly, the teacher-adolescent relationship is still one aspect of the adult-adolescent relationships, and therefore it shares some similar features with adolescents' relationships with parents. Although many studies still use teacher support as a composite concept representing a variety of teacher behaviours (Suldo et al., 2008; Frey et al., 2009), there are increasing studies investigating the detailed concepts of teacher support compatible with parent support. For example, warm, consistent and less coercive teachers have been shown to predict higher student help-seeking behaviour (and lower concealment) in academic problems among young adolescents (age 9-12) in the US (Marchand and Skinner, 2007). Psychological bonding with school staff is also generally related to fewer behavioural problems in adolescence (Crosnoe and Needham, 2004; Idsoe et al., 2008; Nation et al., 2008). Although there are fewer studies of the teacher-adolescent relationship than the parent-adolescent relationship, these studies all seem to suggest that adolescents benefit from teachers adopting strategies used in the family environment in early adolescence, i.e. adult involvement, school warmth and autonomy support.

Parent support and teacher support have also been compared more explicitly in studies published in the past few years. In a study concerning bullying behaviour among 13 year-old Finnish adolescents, parent-adolescent and teacher-adolescent relationships were investigated in three dimensions: emotional connection with adolescents, adults' knowledge of adolescent behaviour and parental over-protection.

In general, these dimensions were compatible with adult involvement, warmth and autonomy support. As a result, parents' and teachers' knowledge of adolescent behaviour were significantly associated with less bullying behaviour, while over-protection from parents and teachers was not associated (Idsoe et al., 2008). On the other hand, emotional connection was not directly associated with bullying behaviour, but associated with parental knowledge of adolescent behaviour and over-protection. The authors explained that although adult-adolescent connection did not affect behaviour directly, it was a factor that enhanced adult knowledge of adolescent behaviour and adult autonomy support (as a reverse concept of adult over-protection). In short, this study seems to suggest that adult involvement is more important than autonomy support in preventing adolescent aggressive behaviour, and the result can be true for both parents and teachers. This is a *deja-vu* -- recalling the discussion in the previous section where the family environment in early adolescence was reviewed, there are consistent studies showing the isolated benefits of parental involvement, warmth and autonomy support in adolescent academic, psychological and social outcomes. However, there is no consistent conclusion on the coexistence of parental involvement and autonomy support. Therefore, to understand the effects and mechanisms of different dimensions in adult-adolescent relationships, more observational and interventional studies will be required. Nevertheless, this study demonstrates the similarities in the roles of parents and teachers in young adolescents' social lives.

As expected, differential impacts from parent support and teacher support have also been gradually shown in recent studies. In a study involving two groups of mid-adolescents ( $n=328$  and  $285$ ), autonomy support was defined by the degree to which adolescents perceived that they were encouraged by parents or teachers to pursue their own interests and values. The study concerned the relationship between autonomy support and adolescent self-determination (self-control) or academic/behavioural outcomes. As a result, self-determination in school performance was predicted by

teachers' and mothers' autonomy support, while self-determination in friendships was predicted only by mothers' autonomy support, but not by teachers' autonomy support. The two aspects of self-determination (school performance and friendship) also respectively predicted domain-specific outcomes (school performance and social competence). The study seems to suggest that mothers and teachers play differential roles in supporting adolescent autonomy in mid-adolescence -- teachers seem to have impact on adolescent behaviour or outcomes more specifically in the formal school context. Another interesting aspect in this study was the inclusion of fathers' autonomy support in a sub-sample, which however did not predict adolescents' self-determination either in school performance or in friendships (Soenens and Veansteenkiste, 2005).

Although there are fewer studies of teacher-adolescent relationships than of parent-adolescent relationships, current evidence seems to suggest that these two types of adult-adolescent relationships share more similarities than differences. The differences are possibly the result of school transition, which make young adolescents experience the loss of support from teachers more rapidly, and receive more specific benefits from teachers only within the school context. To investigate the social environment in early adolescence, the teachers' point of view still requires further exploration to confirm these findings. This thesis focuses on the social environment of asthma adherence: parents' and teachers' view on this issue were both explored qualitatively via semi-structured interviews. These are presented in chapter 5.

## **Social life with peers and social competence**

### *A brief summary of previous discussion*

The discussion of the life of young adolescents in this chapter has been extended from adolescent self-concept to their social environment. Concerning a specific

behaviour or a specific group of behaviours (asthma management for instance), behaviour-specific social support from others represents an explicit way of influence from the social environment. However, behaviour-specific social support is only one aspect of the social environment -- behaviour can also be influenced by less behaviour-specific aspects of the social environment, such as socioeconomic status and social capital. However, the impacts of socioeconomic status and social capital on a person's life are usually context-dependent, which makes exploring the relevant context an important approach to link the social environment and the behaviour. Since this thesis concerns asthma management in early adolescence, it is not possible to disentangle the social environment of asthma management in early adolescence without knowing a young adolescent's social life. Therefore, recent literature is reviewed, starting by describing the change and the impact of parent-adolescent relationships and teacher-adolescent relationships. They are the most important adult-adolescent relationships in the family environment and the school environment. Studies have also shown the general benefits of adult involvement, warmth, and autonomy support for early adolescents. As this chapter moves to a more specific context in young adolescents' asthma management, these concepts will help develop the hypotheses of this thesis.

### *Peer environment*

In contrast to experiences with parents and teachers, experiences with peers in early adolescence are very different. Although we may also imagine that peers develop trust, warmth and communication, adult-related activities such as supervision and autonomy support generally do not apply. In fact, early adolescence may be a period of school bullying and victimization, at least in western countries (Nation et al., 2008; Camodeca and Goossens, 2005; Bellmore and Cillessen, 2006). Peer victimization is related to subsequent decline of social self-concept, and peer stress is related to subsequent social disengagement (Bellmore and Cillessen, 2006; Caldwell

et al., 2004). On the other hand, bullies are no better than victims. Compared to intimacy and popularity, children who seek social dominance in their friendships also tend to have more disruptive behaviour and low school achievement (Kiefer and Ryan, 2008). Meanwhile, one study has shown that having friends with aggressive behaviour and peer victimization was also associated with poorer academic achievement at age 9 (Schwartz et al., 2008). Therefore, having a supportive peer environment is important not only because it is young adolescents who are bullies or victims who may suffer, but also peers who witness bullies or victims.

Another important aspect of a supportive peer environment is belongingness -- adolescents seem to benefit from having a sense of belonging among peer groups. Those with clearer peer identity tend to have higher self-esteem, and those who fail to establish a sense of belonging or who have negative peer experiences in a peer group are more likely to have social dissatisfaction, behavioural problems and academic maladjustment (Galanaki et al., 2008; Schwartz et al., 2008; Tarrant et al., 2006; Brendgen et al., 2002; Juvonen et al., 2000). Therefore, adolescents not only seek a peer environment without bullying and victimisation, but also a peer group which they can identify with.

### *Peer relationships and social competence*

While studies in adult-adolescent relationships tend to focus on adult characteristics that support adolescents, literature in peer relationships usually covers a different range of topics -- unlike the relationships with adults where adolescents usually receive support, peer relationships are usually more mutually balanced, and sometimes adolescents are encouraged to play an active role by improving their *social skills or social competence* in order to create a more supportive peer environment.

One way to understand peer social competence is through its purpose -- since the

purpose of peer social competence is to create a supportive peer environment, it is not surprising to see a large number of studies evaluating peer social competence with *peer acceptance*. *Peer nomination* is commonly used in studies to evaluate peer acceptance of children. Peers were asked to nominate friends with specific features in their class (most close friend, trustable friend, aggressive friend, etc.), and peer acceptance of a child is calculated by combining reports from all peer responses. This is frequently referred to as *sociometry*, and sociometric peer acceptance has been found to be associated with academic and psychological outcomes among younger children (Schwartz et al., 2005). However, it is difficult to decide who to nominate among older adolescents when their activities are no longer limited to their classmates. In a study where the peer nomination strategy was compared between grademates inside and outside the classroom in secondary schools, scores from different nomination strategies (inside or outside the classroom) had differential correlations with teacher-rated anti-social behaviour and school achievements, and in fact, the correlations were stronger when reports of grademates outside the classroom were used (Poulin and Dishion, 2008). Therefore, although peer report seems an authentic measure for peer acceptance, there are limitations to this measure when adolescents start to experience a broader peer environment, especially in secondary school. However, this is not the only methodological issue of peer acceptance. In a study carried out in Slovenia, sociometric peer like-ability and sociometric peer popularity were compared among adolescents aged 11-17. Compared to students in primary school, secondary students tended to have differential nominations for different descriptors (Kosir and Pejak, 2005). Perceived by peers, people who are most likable may not be the most popular, and vice versa. Therefore, as adolescents explore a broader peer environment, peer acceptance has a more differentiated meaning for adolescents.

Apart from peer nomination, peer acceptance has been evaluated by adults in a number of studies, and teacher-reported peer acceptance has also been associated with

academic and psychological outcomes. In the UCLA Family Development Study (n=677), lower teacher-reported peer acceptance at age 10 predicted poorer psychological adjustments at age 12, and this predictive effect remained when the effect of close friend support was controlled for (Klima and Repetti, 2008), suggesting that adolescents not only seek close friendships, but also popularity among a larger crowd, and teachers may be an alternative source in understanding peer acceptance of adolescents beyond their close friendships. These results are replicated in a study among a Chinese adolescent population, where the reciprocal prediction between peer-assessed and teacher-assessed peer acceptance and academic performance was also found in young people at age 9 and age 12 (Chen et al., 2008). Therefore, the importance of peer acceptance from both peers' and teachers' perspectives may also have some consistencies across cultures.

Apart from peer acceptance reported by peers and adults, self-reported peer acceptance (or social self-concept) may be considered to represent another aspect of peer acceptance. As seen in other self-concept studies, adolescents' social self-concept changes as they grow. The developmental change of perceived (or self-reported) peer acceptance has been investigated in a longitudinal study among 197 families where children at age 9-11 were followed for 6 years, and a curvilinear time-dependent curve of perceived peer acceptance was demonstrated -- perceived peer acceptance increased gradually from 9 years old and then decreased gradually from 12-14 years old (Kim et al., 2007). Although it may seem more objective to evaluate peer acceptance from others (but not from self), the argument that adolescents are accepted by peers may still be incomplete if they do not perceive themselves as accepted by peers. Therefore, perceived peer acceptance is sometimes used in composite scores to evaluate peer acceptance with self and other reports jointly. In a longitudinal study, for example, relationships between peer acceptance and psychological adjustment were investigated among 205 children aged 8-12, who were then followed up at 7, 10 and 20 years. The peer acceptance score was a composite of

peer nomination, family interview results and self-report; the measures were changed at each time point to suit the age of participants. As a result, peer acceptance at baseline predicted future peer acceptance at least up to 10 years. A high level of peer acceptance at age 8-12 also predicted a lower level of internalising problems in 7 years, which then predicted future internalising and externalising problems. However, there was no significant path that suggested a direct effect of peer acceptance at age 8-12 on future externalising problems in this sample (Burt et al., 2008). In short, this study suggests that peer acceptance in early adolescence is usually stable across adolescence, and associated with internalised and externalised psychological adjustment in the following years.

So far the discussion has focused on the evaluation of peer social acceptance. Although by definition the most authentic way to assess peer social acceptance is through peer-reported acceptance, some methodological difficulties are reviewed that may affect the validity of this approach. On the other hand, adult-reported and self reported measures provide objective and subjective perspectives of peer acceptance. Considering the comprehensive knowledge of peer acceptance, a combination of multiple perspectives seems a more appropriate way to approach the dynamic peer environment in early adolescence.

### *Prosocial behaviour and coping activities*

Most studies of peer acceptance are observational studies which investigate the associations between peer acceptance and adolescent outcomes. However, peer acceptance is only an assessment of the *representations* of social competence, whilst the *mechanisms* of social competence are also important. Some studies have investigated mechanisms by identifying the adolescent characteristics that predict peer acceptance. In a study carried out in the Netherlands, for example, 6847 junior high school students (age 13) were enrolled in a survey, where sociometric peer acceptance

was measured. Among personal factors, peer acceptance was associated with extraversion and perceived athletic competence, but not with physical attractiveness, agreeableness and age. Meanwhile, the study also found that positive peer acceptance was associated with non-ethnic minority and more primary school mates in the same class (Lubbers et al., 2006). However, this type of study only helps to explain what kind of adolescents tend to be more acceptable by peers, but does not provide suggestions as to how to improve peer acceptance.

In order to improve peer acceptance, a more feasible concept may be *social skills* i.e. how adolescents modify their behaviour or cognitions in order to be accepted by peers. A common concept of social skills is prosocial behaviour, which is socially appropriate behaviour that is assumed to create a supportive peer environment. For example, using the Social Skill Rating Scale (SSRS), cooperative, assertive and self-control behaviour of children was assessed as peer social skills at age 10. Children who performed at a higher level of social skills achieved better academic outcomes and perceived more peer support when they were followed up 9 months later (Elias and Haynes, 2008). SSRS was also negatively associated with concurrent and future anti-social behaviour in a Norwegian study where 13 year old adolescents (n=391) were followed for 17 months (Sorlie et al., 2008). In general, these studies seem to suggest that being cooperative, assertive and self-controlled is helpful in adolescents' academic and social outcomes.

Moreover, there has been evidence showing the benefits of prosocial behaviour in an adverse peer environment. In the US, 576 students (age 13) were followed for 3 years to investigate the impact of social skills in the school context on academic achievement. Social skills were measured by prosocial/antisocial behaviour (self and teacher report) and decision making abilities (self and parent report). School context included peer problem behaviours and bonding/commitment to school. As a result, controlling for baseline academic achievement and student attention problems, better

academic achievement (followed for 3 years) was independently predicted by better social skills (more prosocial and less antisocial behaviour), less peer problem behaviour and higher commitment to school (Fleming et al., 2005). Therefore, the study suggests that adolescents' social skills and the peer environment are both independent predictors of academic achievement. When the peer environment is not supportive, being socially competent may help to compensate for the negative impact of the peer environment on academic achievement.

However, prosocial behaviour can also be just a natural reaction to a warm peer environment. In a study carried out by McElhaney et al. (2008a), peer nomination and self-reported peer acceptance were compared to predict peer-reported prosocial and antisocial behaviours among 164 adolescents (age 13) after one year. High levels of peer acceptance significantly predicted more peer-reported companionship and advice seeking/receiving behaviour, and less peer-reported aggression and withdrawal. Meanwhile, there was a negative interaction effect between the two measures of peer acceptance, indicating that a high level of self-reported peer acceptance reduced the degree peer nominations explain the outcomes, and vice versa. The authors explained that it was possible to feel socially acceptable without being generally popular, and therefore adolescents who perceived themselves as socially acceptable did not try to act pro-socially to gain peer support from a larger crowd (McElhaney et al., 2008a). Regardless of the interaction effect, the main effect in the study suggests a positive correlation between peer acceptance and prosocial behaviour. In other words, although there has been evidence supporting the finding that adolescents receive benefits from acting pro-socially in an unfriendly peer environment, an unfriendly peer environment generally predicts less prosocial behaviour.

To encourage prosocial behaviour among adolescents, further investigation was undertaken to explain how prosocial behaviour can be adopted under adverse peer environments. Adolescents' stress-coping activities appear to be a major topic in this

investigation -- in general, stress-coping activities refer to human reactions to stress, including cognitive, emotional or behavioural reactions. Many studies have investigated the use of different patterns or strategies of stress-coping in adolescents, but the results are controversial. In the Coping Strategies Checklist for Children (CSCC), a four-factor structure was established among an American young adolescent population (age 10-12), including active, avoidance, distraction and support seeking (Ayers et al., 1996). However, this factor structure could not be replicated in a Dutch population of the same ages, where two separate dimensions, positive cognitive restructuring and direct problem solving, replaced the original active coping as a single dimension (de Boo and Wichert, 2009). Therefore, the coping strategies adopted by young adolescents may not be static, and they may have different patterns under different contexts.

This “*social context of coping*” (Folkman et al., 1991) has not been investigated in adolescents until recently. In a study where the coping activities of 487 Australian students in school years 8, 9 and 10 (approximately age 12-15 years) were investigated, the Coping Strategies Checklists for Children was used, and the coping activities were classified into active coping, avoidance coping and wishful thinking. Patterns of coping activities reacting to adolescent-nominated school and family problems were compared. Compared to school problems, adolescents tended to use more avoidance coping and wishful thinking in family problems (Zimmer-Gembeck and Locke, 2007). The study therefore pinpointed the need to investigate adolescents’ coping in a context-dependent manner.

Although coping activities are complicated and context-dependent, clearer results are seen among studies which focus on smaller topics of coping. Decision-making appears to be a major focus. In the “4-H” study (Gestsdottir and Lerner, 2007), for example, a measure of the tendency of intentional self-regulation was developed to describe how each person reacts to a combination of expected and

unexpected events. Self-regulatory activities were goal setting, goal attainment maximising, and the ability to be flexible when facing difficulties. The study demonstrated a predictive association between intentional self-regulation at 11 years old and a “5C” composite score that represented positive youth characteristics at 12 years old, including confidence, competence, connection, caring, and character (Gestsdottir and Lerner, 2007).

Another major focus in stress-coping research is emotional regulation. For example, coping styles in reaction to anger were investigated among young adolescents (age 9-13) in a 5-year follow up. Factor analysis resulted in six types of coping activities: confronting, redirection of attention, ignoring, reconciliation/explanation, self-blaming and humour. When they were 5 years older (age 14-18), they adopted significantly more reconciliation/explanation and humour strategies, and fewer confronting, redirection of attention, ignoring and self-blaming (von Salisch and Vogelgesang, 2005). In other words, reconciliation/explanation and humour seem to be a sign of maturity compared to confronting, redirection, ignoring and self-blaming. In addition to emotional regulation for anger, emotional regulation for anxiety has also been demonstrated in the literature. For example, among 383 young adolescents (age 12-13), a higher level of social anxiety was defined as fear of negative evaluation and social avoidance, which was associated with poorer self-reported social appraisals (measured with simulation tasks). Social anxiety was also associated with more self- and peer-reported peer victimization and less popularity (measured by peer nominations) (Flanagan et al., 2008). This study seems to suggest that social anxiety is associated with adolescents’ appraisals of social situations. This is also supported by an intervention which focused on information-processing skills to appraise social situations more friendly (less hostile) and henceforth to promote pro-social behaviour among 10 year old students (Fraser et al., 2005).

Decision making and emotional regulation are commonly referred to as important

elements of social skills (Kimber et al., 2008; Sorlie and Ogden, 2007; Fraser et al., 2005). Although there have been inconsistencies in the patterns of coping activities, coping activities seem to be roughly classified into two broad types related to decision making and emotional regulation: a common type of coping concerns how psychological stress is cognitively processed, such as avoiding, accepting or emotional coping (Peeters et al., 2008; Peyrot et al., 1999). However, this cognitive coping ignores a human's ability to react to the environment by interacting with the environment. "Approaching" coping styles, such as decision making or seeking understanding, are used in the literature to describe this environment-interacting coping style (Zimmer-Gembeck and Locke, 2007; Weaver et al., 2005). This avoiding-approaching coping classification has been frequently used in the coping literature. For example, using computer-aided scenario-based tasks, the coping activities of young adolescents (age 10-13) were investigated in peer-rejection and non-rejection simulated scenarios in one study. The results showed that rejection caused a negative emotion in the study, but this effect was attenuated among adolescents who perceived themselves to be socially accepted. Meanwhile, negative emotions were associated with avoidance coping behaviour, and perceived social acceptance was associated with more problem-solving based coping behaviour (Reijntjes et al., 2006b; Reijntjes et al., 2006a). In short, it seems that adolescents tend to adopt avoidance strategies when they have negative emotional responses, but feeling accepted among peers reduces these negative emotional responses so that they can be then engaged in problem solving activities.

#### *Adults and peers: who is important?*

Of the peer environment reviewed so far, the discussion starts by describing a peer environment that supports favourable academic and behavioural outcomes, characterised by warm peer relationships and a sense of belonging. Unlike the relationships with adults, peer relationships are more balanced in power, and

adolescents need to develop peer social competence in order to create a supportive peer environment. Then the discussion moved to the meanings of peer social competence, starting with a general evaluation of social competence, i.e. peer acceptance, from the perspectives of self, adults, or peers. Afterwards, prosocial behaviour and stress-coping activities were reviewed to approach peer social competence as a behavioural aspect of social competence (in contrast to peer acceptance as an evaluative aspect). Although there has not been a consistent way to classify stress-coping patterns, decision making and emotional regulation have been the social skills most frequently investigated in the literature. By developing these skills, adolescents are expected to develop more pro-social behaviour, react to stress more easily, and contribute to a supportive peer environment. Again, these all describe the relatedness of peer relationships, therefore, they are the elements of *social capital* within the peer environment.

Furthermore, taking an aerial view of the social environment in early adolescence, peer environment constitutes only a part of the social environment. Therefore, as young adolescents react to the peer environment, they also react to all significant others simultaneously, particularly the parents and teachers. This thesis also considers the different meanings of the social environment of adolescent behaviour, especially specific social support and social capital. Considering a behaviour or a group of behaviours (asthma management for instance), although it is relatively straightforward to describe the impact of specific social support by summarising (or aggregating) the attitudes of all significant others (as seen in the theory of Planned Behaviour), there is no simple way to aggregate the indirect impact of multi-dimensional social capital. Or more precisely, to understand the impact of multi-dimensional social capital, broader studies are required to delineate adolescents' behaviour within the composite social environment.

This does not mean that there have been no attempts. One common approach

focuses on the relative or independent impacts of different social domains on adolescent outcomes. However, because there are usually too many aspects of the social environment to consider, only selective factors can be included, and the results are difficult to interpret and compare. For example, the Italian Health-Behaviour in School-aged Children (HBSC) Project concerned self-reported bullying behaviour and victimization. Adolescent-perceived peer acceptance and adolescent decision-making autonomy (self-determination) from teachers, parents and friends were compared among 11, 13, and 15 year-old adolescents. This cross-sectional study investigated the roles of adolescent autonomy and peer acceptance in explaining bullying behaviour and victimization at 11, 13, and 15 years old. Surprisingly, among 13 and 15 year-olds, bullying behaviour was associated with higher perceived peer acceptance and lower decision-making autonomy from teachers, but not associated with decision-making autonomy from parents and friends. Being victimised, on the other hand, was associated with lower perceived peer acceptance (15 year-olds only) and lower decision-making autonomy from parents, but not associated with decision-making autonomy from teachers or peers. In contrast to older adolescents, bullying and being victimised among 11 year-old adolescents were not associated with perceived peer acceptance, but both were associated with lower decision-making autonomy from teachers (Nation et al., 2008). The authors concluded that there were consistent benefits of decision-making autonomy from teachers across all years in early adolescence. However, interpretation is difficult. For example, decision-making autonomy is not the only aspect of adult support, and as discussed earlier, the controversy between the benefits of adult involvement and adult autonomy support may complicate this knowledge. An alternative explanation can be adults' tendency to support autonomy for adolescents who do not have bullying or victimization problems. Therefore, it is still not possible to establish causal relationships between autonomy support and bullying behaviour from this type of studies.

Instead of comparing the impact of different social domains (or social

environments), researchers have also started to describe the interdependency between different domains of a social life. For example, a warm relationship with adults seems to be associated with pleasant peer relationships in early adolescence. In the Profiles of Student Life: Attitudes and Behaviours (PSL-AB) survey, perceived peer acceptance of American adolescents aged 11-13 was predicted by more family communication, warm family relationships and consistent family rules (Hillaker et al., 2008). A warm family life is also associated with prosocial behaviour that predicts pleasant peer relationships. In a longitudinal study among 214 families, for example, parental emotional expressiveness at age 6 predicted child-reported and teacher-reported sympathy and child-reported prosocial behaviour at age 14 (Michalik et al., 2007).

Moreover, adult-adolescent relationships may also affect adolescent stress-coping patterns. The Zimmer-Gembeck & Locke study which was introduced earlier in this chapter demonstrated context-dependent coping patterns among 487 adolescents (age=14) at school and at home. The same study also investigated whether or not the coping patterns were associated with adolescents' relationships with parents and teachers. The parent-adolescent and teacher-adolescent relationships were described with a composite score consisting of adult involvement and autonomy support. As a result, a positive parent-adolescent relationship was associated with approaching (or problem-solving) coping strategies at home and at school, and a positive teacher-adolescent relationship was associated with approaching coping strategies specifically at school (but not at home) (Zimmer-Gembeck and Locke, 2007). As mentioned earlier, approaching coping strategies are associated with prosocial behaviour and peer acceptance (Reijntjes et al., 2006a; Reijntjes et al., 2006b). Therefore, the study also provides indirect evidence to support the link between a warm adult-adolescent relationship and warm peer relationships. Compared to parents, teacher-adolescent relationships are less investigated in the literature along with other social relationships in early adolescence. However, this single study seems

to agree with another study described earlier (Soenens and Veansteenkiste, 2005) in the specificity of teacher influence only within academic contexts.

So far all the evidence seems to suggest that warm adult-adolescent relationships predict supportive peer relationships. This may not always be true. In a study carried out in China, the moderating effects of peer group types on parent-adolescent relationships were demonstrated among 11 year-old adolescents followed for one year. Adolescents who reported themselves in prosocial peer groups received benefit from maternal warmth and responsiveness (reported by parents), i.e. those whose parents report higher level of warm and responsive support had higher levels of peer preference and academic performance, and a lower level of problem behaviour. By contrast, adolescents who reported themselves in antisocial peer groups were associated with an opposite effect. Parent-reported warmth and responsiveness were associated with a lower level of peer preference, a lower level of academic performance, and a higher level of problem behaviour in 1 year follow up (Chen et al., 2005). As expected, the results become difficult to interpret when many elements of a social life are considered in a study. This study, for example, is based on parent-reported family relationships and adolescent-reported peer preference. It is not clear how these associations were subject to report biases (e.g. parent-perceived family warmth may not reflect the true level of adolescent-perceived family warmth). Meanwhile, this correlational study cannot distinguish between causes and effects. Admitting all these research limitations, the study still confirms the findings of other studies in the positive associations among all positive attributes of different aspects of the social environment. Therefore, “the winner takes all” – adolescents who had poor family relationships (or relationships with adults) tended to have problems among peers. According to this study, moreover, having anti-social peers may in turn stop adolescents from being supported by adults.

However, this winner-takes-all situation is only a simplified conclusion. What is

learned from the literature is that despite the general benefits from parents being supportive, the mode of support does matter, and the benefits may also depend on subgroups of adolescents, such as their peer groups (or peer identifications). More studies will be required to explain how young adolescents react to “contradictory” social environments. Among the limited studies on this topic so far, many studies still focus on the association between adolescent relationships with parents and with peers. When adolescents are unfortunately facing a non-supportive family and non-supportive peer environment, it is important to see how their relationships with teachers can modify this adverse situation.

### *Summary*

Three important aspects of young adolescents’ social environment (parents, teachers and peers) have been reviewed in this section. Evidence in educational and developmental psychology has suggested a different focus in each type of social environment. In adult-adolescent relationships, involvement, warmth and autonomy support seem to have positive impact on adolescent outcomes, although parents and teachers may play differential roles in different life domains. In peer relationships, adolescent social competence plays a key role in a supportive peer environment, but more studies are required to define the critical social skills that improve social competence. Nevertheless, through direct support and indirect influences, the parent-, teacher- and peer-related social environments interact with young adolescents’ psychological development to shape their behaviour, which further predicts their academic and social outcomes.

This thesis, therefore, follows this idea and aims to generalise the theories of the social environment into a different context – adolescents with chronic illnesses. In this thesis, asthma management (or asthma adherence as an evaluative term) was conceptualised as a special example of adolescent behaviour, which has been shown

at least to predict health outcomes of adolescents with asthma. Therefore, it is hypothesised that these three types of social environment can interact with young adolescents' psychological development to shape their asthma management behaviour.

### **2.3 Social life, asthma adherence and early adolescence**

Young people with asthma start to learn asthma self-care as early as 8-10 years old (McQuaid et al., 2003; Orrell-Valente et al., 2008). At this age, many of them understand the consequences of an asthma attack, learn to take medicine on their own, and generate strategies to improve their adherence (Penza-Clyve et al., 2004). By the age of 12, they are able to name their drugs accurately. They know how to avoid triggers, and some of them can play a decision-making role in taking their inhalers (Pradel et al., 2001; Orrell-Valente et al., 2008). Young adolescents' growing cognitive and social development largely contributes to their ability to be responsible for their own health. However, as mentioned earlier in this chapter, asthma management is not only about taking medications or relieving asthma attacks, but also about life style modifications that prevent the onset of asthma attacks. By contrast, adolescents' cognitive development about these life style modifications is relatively under-investigated in the literature.

Moreover, understanding young adolescents' knowledge of asthma management may not be sufficient in improving asthma management -- the importance of the social environment in adolescent behaviour has been reviewed earlier, and the context-dependency of the social environment has also been emphasised in the literature in educational and developmental psychology. However, although asthma management is conceptualised as one example of adolescent behaviour, it is different from the general behaviour discussed in educational and developmental psychology. Therefore, the following focus is narrowed down to assess the generalisability of

these behavioural and social environmental theories in the context of asthma management. Interestingly, despite the substantial literature concerning the impacts of the social environment on adult health behaviour, the literature specifically considering young adolescents' social environment in medical adherence has just begun in the past 5 years to be informed by our knowledge of educational and developmental psychology. This literature is reviewed in this section and is used to develop the research hypotheses of this thesis. As mentioned, because diabetes management is more recognised as a multi-dimensional construct than asthma management, there is great reliance on the diabetes literature in our knowledge of adolescent chronic illnesses in the family environment and the school environment.

### **Parents and adolescents with chronic illnesses**

Similar to our knowledge of adolescent behaviour, there is evidence supporting the benefits of parental involvement, parental warmth and parental autonomy support in adolescent chronic illnesses. Although contextual differences are still found between general adolescent behaviour and chronic illness management behaviour, the three dimensions of the family environment in early adolescence are used as a backbone of discussion. Among the three dimensions, *parental involvement* refers to family life-sharing, *parental warmth* emphasises family communication and reducing conflicts, and *parental autonomy support* refers to the encouragement or respect for adolescent decision-making.

#### *Parental warmth*

Among parental involvement, warmth and autonomy support, clearer examples have been shown in the literature on parental warmth, but even so the studies published so far are not as strong as those in studies in adolescent general behaviour. For example, in a study where 75 adolescents (age 11-15) with asthma participated,

more severe asthma symptoms and poorer pulmonary functions were seen more commonly among adolescents who reported their parents as less understanding, valuing and caring (Chen et al., 2007b). Although this result demonstrated an association of asthma outcomes and a warm family environment, the mediation effect of asthma management behaviour was not investigated. By contrast, this was demonstrated in another pooled sample study where 200 children and adolescents (age 7-18) with diabetes, asthma or cystic fibrosis participated. Using this sample, the study demonstrated an association between poorer disease self-care behaviour and parenting stress, but not with parent-perceived child vulnerability or parent over-protection (Bourdeau et al., 2007). In this study, self-care behaviour was measured by parent-reported summative evaluation of management behaviours specific to the individual illness the children or adolescents suffered from (diabetes, asthma or cystic fibrosis), which implies the questionnaire items were different for children and adolescents with different illnesses. Therefore, although including children and adolescents with different chronic illnesses helped to increase the sample size and the external validity, the validity and reliability of this heterogeneous questionnaire was not justified.

To confirm the benefits of a warm family environment in disease management, 36 families with adolescents with asthma received a 6-month family intervention in a randomised controlled trial delivered by psychologists emphasising family communication and problem-solving in family disagreement. Compared to the families who received standard care and the families who attended group discussion (as an alternative intervention), the families who received the communication and problem-solving intervention had less family conflicts, better asthma adherence and better disease control following the intervention (Wysocki et al., 2006). Therefore, although stronger studies are required to confirm the results, current observational and interventional literature seems to support the finding that a warm family, characterised by minimal conflicts and effective communication, has positive impact on disease

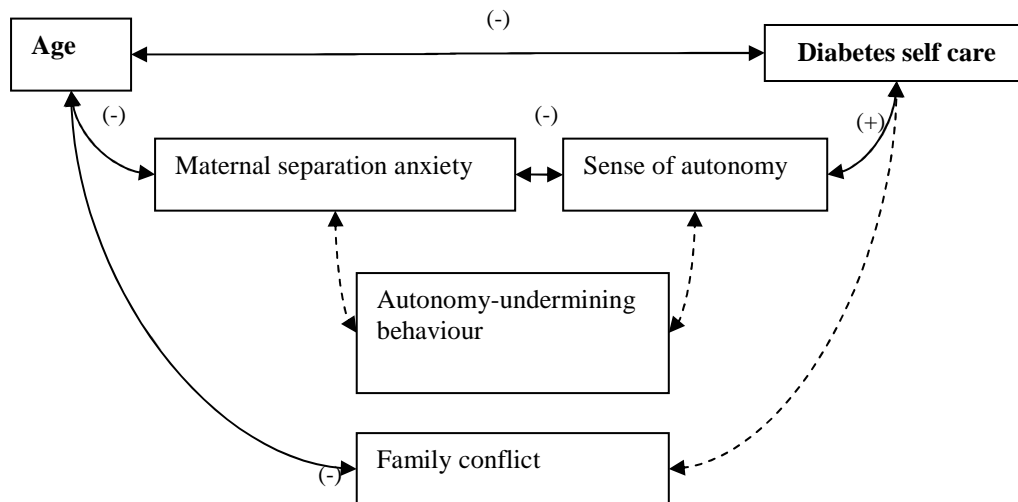
management in early adolescence.

### *Parental involvement and parental autonomy support*

Compared to parental warmth, parental involvement and parental autonomy support received equal attention from researchers, but the conclusions are less affirmative. Recalling the discussion earlier about the family environment of a young adolescent, there have been controversial results in the coexistence of parental involvement and autonomy support -- although parental involvement and parental autonomy support both predict favourable adolescent outcomes, a higher level of parental involvement in adolescent activities was associated with more fear of crime when the level of autonomy support was controlled for (De Groof, 2008). In the literature of chronic illnesses (in diabetes primarily), there have not been many studies distinguishing high parental involvement (high level of life sharing) from low autonomy support (parental dominance in decision making), and thus it is more difficult to generalise the literature in educational psychology to chronic disease management. For example, the relationship between parental involvement in adolescent stressful scenarios and adolescent psychological outcomes was investigated among 127 adolescents (age 10-15) with diabetes in the US. Adolescents were asked to assign "involvement types" of their parents into four categories: non-involvement, supportive involvement (provide suggestions), collaborative involvement (work together) and controlling. As a result, compared to other parental involvement types, parental collaborative involvement was associated with better diabetic adherence and better disease control. Parental control, on the other hand, was associated with a higher level of adolescent depression, poorer adolescent quality of life and lower life satisfaction among older adolescents, but not among younger adolescents (Berg et al., 2007; Wiebe et al., 2005). At one level, the study seems to suggest a need for more decision-making autonomy (i.e. less parental control) for older adolescents. However, parental control was conceptualised as a type of parental

involvement, and this approach made “parental decision-making dominance” and “parental sharing adolescent life” indistinguishable.

Figure 2-4 Age, autonomy and self care in adolescent diabetes (Dashiff et al., 2009). Solid lines show significant relationships; dashed lines show non-significant relationships.



Development of autonomy in adolescent diabetic self-care behaviour was also investigated in a longitudinal study where 183 families of adolescents (age 11-15) with diabetes were followed for 2 years (figure 2-4). Consistent with other studies, older age was associated with poorer self-care behaviour (reported by adolescents), but also associated with less maternal separation anxiety and less family conflict (reported by mothers). Meanwhile, better self-care behaviour was predicted by adolescents’ sense of autonomy after a 1-year follow-up. Greater sense of autonomy, in turn, was predicted by less maternal separation anxiety, but not predicted by family conflict or maternal behaviour that undermined autonomy and relatedness one year before (Dashiff et al., 2009). In other words, there was a trend across age 11-15 that self-care behaviour became poorer at an older age, but poorer self-care behaviour was also a result of a poorer sense of adolescent autonomy and a higher level of maternal separation anxiety. However, the study failed to explain the link between maternal autonomy-undermining behaviour and the sense of adolescent autonomy. Therefore, the study supports a positive effect of adolescent sense of autonomy on disease

management, but there may be other mechanisms that explain the link between maternal separation anxiety and adolescent sense of autonomy independent of these maternal autonomy-undermining behaviours.

There have also been attempts to approach adolescent autonomy using more sophisticated quantitative methods. Among 185 families with adolescents (age 10-14) with diabetes, mother-adolescent and father-adolescent discrepancies on disease management competencies were calculated with structural equation modelling. Briefly, the discrepancies were compositions of residual variances of four parent-reported diabetic management competencies when correspondent adolescent-rated items were controlled for (therefore they were residual variances). The four competencies included parent-rated adolescent adherence, adolescent efficacy, adolescent behavioural independence and adolescent problems with diabetes. The purpose of the study was to investigate whether these discrepancies were associated with adolescent or parent outcomes in the following month. Adolescent outcomes included diabetic control and depressive symptoms, while parent outcomes included depressive symptoms, marital satisfaction, environmental mastery and purpose in life. In this study, parents generally reported poorer performance of adolescents than adolescents' self reports in all four diabetic management competencies, and a higher level of adult-adolescent discrepancy was associated with (adolescent-reported) parent autonomy-encouraging behaviour and the sense of autonomy. Meanwhile, mother-adolescent discrepancy predicted poorer diabetic control and poorer *maternal* psychological adjustment in all aspects, but it did not predict adolescent or paternal psychological adjustment. In contrast to mother-adolescent discrepancy, father-adolescent discrepancy only predicted lower senses of father-perceived purpose in life, but it did not predict other aspects of father psychological adjustment, nor did it predict adolescent or mother outcomes (Butner et al., 2009). The researchers argued that maternal-adolescent discrepancy reflected adolescent autonomy, which was associated with poorer diabetic control and poorer maternal psychological outcomes.

Again, this definition of adolescent autonomy is not distinguishable from parental involvement (adolescent life sharing). Therefore, the negative impact of parental autonomy support may also be due to the negative correlation between parental involvement and parental autonomy support.

So far the three dimensions of the family environment in early adolescence, parental involvement, warmth and autonomy support, have been re-examined in the context of chronic illness management. Many well-developed studies have been published in the past 5 years, and more studies are required to confirm these findings. Although the current literature supports the positive role of a warm family environment in adolescent disease management, there are controversies in the definitions of parental involvement and autonomy support, resulting in difficulties in interpretation of the results. On the other hand, it should also not be surprising that these three dimensions in the family environment of adolescent general behaviour may not be the optimal characteristics that describe the family environment of chronic illness management. Most importantly, if there are differences between general behaviour and diabetes management behaviour, how these differences can be generalised into the context of adolescent asthma also requires investigation. Therefore, having recognised the mass literature in the family environment of early adolescence, it is still necessary to explore the family environment in the special context of young adolescents' asthma management in a qualitative way. This is presented in chapter 5.

### *Responsibility*

Apart from the three-dimensional family environment in the literature in developmental psychology, many diabetes studies use *responsibility* to conceptualise parental support in disease management. Not surprisingly, older adolescents were more likely to think of diabetes management as their responsibility, and young

adolescents reported that diabetes management was a responsibility shared by them and their parents (Beveridge et al., 2005). Further studies have investigated the relationship between responsibility share and disease management -- in Helgeson et al.'s study, based on parent and adolescent report, the family responsibility for disease management among 132 adolescents with diabetes (age 10-14) was categorised into parent responsibility, child responsibility and shared responsibility. After three years, families with shared responsibility at baseline were associated with better concurrent and predictive psychological outcomes, disease control and self-care behaviour (Helgeson et al., 2008). The study seems to suggest that evenly-shared responsibility in a family is the optimal strategy in early adolescent diabetes management. Instead of finding the optimal strategy for all adolescents, subgroup differences were investigated among 185 adolescents with diabetes in the US (age 10-14). As expected, a lower level of parental responsibility was observed among the adolescents who were older and more physiologically mature, or the adolescents who were more confident with diabetes self-care (reported by themselves or parents). Moreover, although parental responsibility was associated with better disease control, this association was only seen among adolescents with poorer confidence in disease management, but not among adolescents with higher confidence (Palmer et al., 2009). Therefore, the study seems to suggest that the benefits of parental involvement apply only among adolescents who are not prepared to take responsibilities. In other words, instead of assuming evenly-shared responsibility as the best strategy in early adolescence, this study suggests an optimal strategy of responsibility sharing dependent on adolescents' confidence in disease management.

It is important to point out that parental responsibility is neither parental involvement nor parental autonomy support. Parental involvement is life-sharing, and autonomy is a right of decision-making. On the other hand, responsibility is a duty, which does not necessarily imply life-sharing or decision-making. The concept of disease management responsibility is very different from what is seen in the literature

on adolescents' general behaviour -- when pro-social behaviour or aggressive behaviour is concerned, parents cannot "do the prosocial behaviours for adolescents," and thus there is generally no ambiguity in the behavioural responsibility between parents and adolescents. In diabetes, by contrast, there is ambiguity in responsibility (or sense of responsibility), and thus how family relationships interplay with the shift of responsibility becomes an issue. Unfortunately, studies simply observing the shift of responsibility do not provide the answers. Therefore, as the family environment of asthma management was explored in this thesis, the status of responsibility share was also investigated.

### **Teachers and adolescents with chronic illnesses**

Compared to parent-adolescent relationships, teacher-adolescent relationships are almost absent in the literature on adolescent chronic illnesses, and these studies pose greater emphasis on teachers' direct social support towards disease management (e.g. knowledge and attitudes) instead of the quality in teacher-adolescent relationships. For example, in a survey conducted in 2001 where 291 elementary school teachers and 302 middle school teachers in Georgia US completed questionnaires about their knowledge of asthma, most teachers agreed that asthma can only be managed, not cured. Subgroup comparison suggested that middle school teachers are more knowledgeable about asthma than elementary school teachers, and teachers who had chronic illnesses were more knowledgeable about asthma, especially teachers with asthma themselves (Getch and Stacey, 2009; Neuharth-Pritchett and Getch, 2001). However, the role of teachers as professional educators was usually ignored in this type of study, and the application of educational psychology or developmental psychology in teachers' support of asthma care is still rudimentary.

Nevertheless, the absence of teachers in the literature on asthma does not imply an absence of school asthma care. Awareness of school asthma care has been burgeoning

in the past five to ten years. Despite the lack of empirical evidence, expert-based recommendations have been increasingly disseminated (Lara et al., 2002; NHLBI, 2005; Jones and Wheeler, 2004) to highlight the importance of school asthma care. In fact, in another survey in New York where 253 school staff members from 5 elementary schools completed a very brief questionnaire (10 items), they reported a great reliance on school health personnel (Snow et al., 2005). This is probably true. Most school recommendations have been focused on “meeting students’ needs”, mostly by training school staff first-aid knowledge, building a trigger-reducing environment, and providing facilities for students with asthma. School health personnel are usually considered the key person. In a study carried out in the UK, for example, an intervention led by school nurses was conducted to improve morbidity and psychological well-being of children (age 7-9) with asthma. During 2000-2001, 113 pupils in 12 primary schools participated in the intervention where research nurses taught pupils and school staff knowledge of asthma for 45 minutes, including prevalence, symptoms, different inhalers and psychological impact. This was then followed by a workshop for a further 45 minutes where 3 scenarios of asthma attack were discussed as a draw-and-write activity (45 min). The pupils were followed in the next school year. Compared to pupils in the 12 control group schools (n=113) with non-asthma oriented input, pupils in the intervention group reported less requirement for medication, more clinical improvement, higher activity-related quality of life and better self-concept especially in social and behavioural domains, although there was no difference between the two groups in school absences and symptom frequencies (McWhirter et al., 2008; McCann et al., 2006). A similar curriculum also improved asthma symptoms and the days of limited activity among American adolescents in another school nurse-led intervention of a non-controlled trial (Magzamen et al., 2008). Therefore, although well-designed empirical studies in the school have not been seen in the literature, school nurses seem to play a key role in school asthma care.

It is not surprising to see school nurses as a key player in school asthma care. However, such health expert-centred policies have ignored the fact that adherence can be influenced by perceptions and attitudes, and the expertise of other school staff members (e.g. teachers) in children and adolescents' behaviour has often been undervalued. As reviewed earlier in this chapter, the teacher-adolescent relationship is the primary adult-adolescent relationship in the school environment, and it plays an important part in adolescents' behaviour and psychological outcomes, especially in school contexts. If asthma or asthma management has an impact on young adolescents' social life beyond health care, how school staff members support the social impact of asthma management becomes a relevant yet under-investigated question. This question was also explored in this thesis, and the qualitative results were compared to the parent support in chapter 5

### **Peers and adolescents with chronic illnesses**

Unlike most other asthma studies where asthma inhalers are the primary topic, literature on the peer relationships of adolescents with asthma poses great emphasis on smoking behaviour. Many of these studies compared adolescents with and without asthma -- among 3234 middle adolescents in a southern state of the US (age 15-18), 20% of them reported current smoking. Among them, adolescents who reported that they had asthma (15.7%) were 1.5 times more likely to smoke than adolescents who reported that they did not have asthma. Independent risk factors of smoking included older age, African American ethnicity, having best friends smoking, having parents smoking, positive attitudes towards smoking, easy access to tobacco, low perceived social support, high reported stress, and high reported rebelliousness. However, adolescents with and without asthma were influenced equally by these risk factors, and thus the study did not explain clearly why adolescents with asthma were more likely to smoke (Zbikowski et al., 2002). On the other hand, among 1120 smoking adolescents in the Netherlands in a nation-wide survey, only 83 adolescents reported

that they had had asthma in the past 12 months, as acknowledged by their physician, or had taken asthma medication in the past 12 months. Compared to adolescent smokers without asthma, more adolescent smokers with asthma intended to quit smoking, and best friend smoking seemed more important than their parent smoking and their knowledge about smoking in predicting their intention to quit smoking (van Zundert et al., 2008). To compare the two smoking studies, we may not be very confident to conclude whether or not adolescents with asthma are more likely to smoke than adolescents without asthma, but both studies indicated that best friend smoking was an important associative factor of adolescent smoking, with or without asthma.

This influence of peers in the smoking behaviour of adolescents with asthma was confirmed by a matched longitudinal study. In the Add Health Control project (US), 1507 adolescents (Age 11-21) with asthma and 1507 healthy adolescents matched by age, gender, race and geographic area were compared and followed for 1 to 2 years. Twenty percent of adolescents experienced progression in their smoking behaviour, and those with and without asthma were equally likely to progress. More importantly, exposure to friends who smoked was a more consistent and powerful social risk factor for smoking progression among adolescents with asthma than among adolescents without asthma (Tercyak, 2006a). Therefore, at least in smoking behaviour, the peer environment has some impact on adolescents' asthma management.

Apart from smoking behaviour, there is also evidence supporting peer influence on asthma medications. In one study, 126 adolescents with asthma (age 13-20) completed a questionnaire about their perceived barriers of asthma management. Four factors were extracted from the 27-item barrier questionnaire. They were negative attitudes (towards medical regimes), cognitive difficulty, social influence and denial (of having asthma). Interestingly, negative attitudes and cognitive difficulties were associated with non-white race and public (non-private) insurance type (as an

indicator of socioeconomic status), while social influence and denial was associated with gender -- boys reported more social influence and denial (as barriers of asthma adherence) than girls. More importantly, when the effect of self-efficacy was controlled for, the only remaining association was seen between social influence and gender (Rhee et al., 2008). This result suggests that boys perceived social influence as a great barrier even when they were confident in using asthma medications (self-efficacy). Interestingly, this gender-specific effect was also supported by a controlled study of a peer-education intervention in Australia for adolescents with asthma. In the intervention, volunteer adolescents with asthma in year 11 were trained as peer educators, who then taught students in year 10 with teaching tools made by the research group. Afterwards, the year 10 students presented the key messages they learned to year 7 students in short acts, dramas or songs designed by themselves. Compared to adolescents in the control group who received standard care (n=148), adolescents who received interventions in year 7 and year 10 (n=124) reported higher levels of quality of life. There was also a significant trend (pre-/post- differences) of decreased school absenteeism and fewer asthma attacks within the intervention groups, but the between-group difference was not significant. Further analysis indicated the improvement in quality of life was seen in activity domain among both genders, but in emotional domain only among boys (shah et al., 2001). In general, the findings from observational and interventional studies also support an important role of the peer environment in other domains of asthma management (not just in smoking). Although both studies seem to suggest a greater impact of asthma management on boys' social life, more studies are required to confirm this finding.

#### *Peer relationships in chronic illness management*

Although the current literature has demonstrated the importance of peer influence and the benefit of peer education in some aspects of asthma management, there have not been many studies addressing the role of peer relationships in this peer influence. However, there are some studies on adolescents with diabetes that may help

us to understand the peer relationships of adolescents with chronic illnesses. In one study, the quality of the adolescent peer environment was investigated among 76 adolescents with diabetes (age 13-15), including peer conflicts and peer (emotional and instrumental) support. These peer environment indicators were repeatedly reported on by each adolescent for 2 days a month in two separate months; this enabled the effect of intra-individual differences (i.e. monthly differences) and interpersonal differences on diabetic outcomes to be compared. The study suggested that, although peer conflicts were associated with poorer self-care behaviour and poorer diabetic control, this was explained primarily at intra-personal level. In other words, having experienced peer conflicts explains why adolescents sometimes had poorer self-care behaviour, but it did not explain why some adolescents had poorer self-care behaviour than others. In contrast to peer conflicts, there was no effect of peer psychological and instrumental support on diabetic outcomes (Helgeson et al., 2009). Therefore, this study seems to suggest an influence of the quality of peer relationships, rather than the explicit supporting or undermining behaviour of disease management.

To recall from the earlier sections where the peer environment was reviewed, great emphasis was laid on adolescents' peer social competence. Social competence is conceptualised in two ways – on the one hand it is evaluated as social acceptance among peers; on the other hand there are pro-social behaviour and stress-coping activities that contribute to peer acceptance. Meanwhile, peer acceptance and pro-social behaviour are both associated with adolescent academic and behavioural outcomes, but the associations with stress-coping activities were more controversial. Nevertheless, emotional regulation and decision-making skills seemed to be the core stress-coping skills in the limited literature, and approaching (problem-solving) coping strategies seem to be more successful than avoidance coping strategies in gaining peer acceptance.

### *Stress-coping and disease management*

Although there have not been many studies explaining the peer environment in chronic illness management, stress-coping has been a major issue in health promotion studies for decades. In the paediatric population, however, coping attracts more attention in children who are severely ill, especially with cancer. It is hoped that they can “cope well” with the stresses accompanying their illnesses (Edgar and Skinner, 2003; Pretzlik, 1997; Morawska et al., 2008), which usually implies improving their psychological well-being. In other words, coping is considered in one dimension – coping is the reaction to stress; better stress-coping leads to relief of stress, and it is assumed that patients feeling less stressful are more successful in managing their diseases (Audrain et al., 1999). This point of view has also been supported by intervention studies among adolescents with diabetes. A randomised controlled trial was conducted for children and adolescents (age 8-12) with diabetes in the US to compare two interventions, coping skill training (n=54) and group education (n=33), in their effects on adolescent disease control and psychological adjustment. The coping skill training intervention emphasised communication, conflict resolving and stress management, while the group education focused on the knowledge and skills of diabetic self-care behaviour. Although there was no difference between the two groups in psychological adjustment, better disease control was seen in children and adolescents in the coping skill training group. They also reported better self-efficacy in self-care and better quality of life at immediate (1 month) and later (3 month) follow-up (Ambrosino et al., 2008). In this intervention, coping strategies were taught primarily to relieve life stresses, which may help them to manage the diseases.

However, relieving the stress is not the same as managing the disease. Stress-coping strategies might be adopted to relieve stress, but more and more researchers in health psychology have used multidimensional frameworks to examine stress-coping, at least in adult chronic illnesses. Instead of focusing on relief of stress, certain

patterns of coping have been found to be more effective in improving medical adherence in chronic illnesses (Peyrot et al., 1999; Stewart et al., 2003) -- *avoidance* coping strategies, such as denial and behavioural disengagement, are associated with poorer adherence; *approaching* strategies (e.g. acceptance, positive reinterpretation), on the other hand, are associated with better adherence (Weaver et al., 2005; Greenhouse et al., 2000). From this perspective, coping is not only a reaction to stress, but also a pattern of decision making.

This is not to say that coping patterns are simply attributed to a personal trait. A person can react to stress differently in different situations, and there is no single strategy that can be successfully applied in all stressful conditions. For example, in a study of adherence in 57 patients who needed haemodialysis, coping was measured in relation to facing uncontrollable stressors, such as administration of the dialysis procedure, and in relation to facing relatively controllable stressors, such as fluid or food intake self management. As a result, problem solving-oriented coping was associated with better adherence in response to relatively controllable stressors, and emotion-oriented coping was associated with better adherence in response to uncontrollable stressors (Christensen et al., 1995). This literature is different from other studies (which give more emphasis to approaching strategies) in arguing that each coping strategy may have its role in dealing with life stress and medical adherence. Therefore, one intervention approach of this point of view is educating adolescents in social skills so that they can learn the social skills and select their strategies in reaction to different social stresses. In a small non-controlled study in Sweden, 32 adolescents (age 12-17) with diabetes completed a 6-week training focusing on problem solving and emotional regulation in stress coping via small group discussions. The researchers demonstrated a benefit of this training in disease control for 12 months especially among older adolescents (age 15-17), but then the level of disease control declined to the baseline. However, there was no control group to compare in this study, and the actually problem solving and coping activities of the

adolescents were not monitored (Viklund et al., 2007). Therefore, the effectiveness of this approach requires further studies to investigate.

Although the studies discussed above emphasise stress-coping in diabetes management, an association was only established between stress-coping and disease control, and not between stress-coping and disease management behaviour. Although peer relationships are a primary source of young adolescents' life stress, there has been no study demonstrating the relationships between stress-coping activities and peer relationships in chronic illnesses. Meanwhile, for adolescents with diabetes and asthma, stress is also a biological trigger of disease progression (e.g. emotional disturbance may trigger asthma attacks). Therefore, stress can be an independent cause of poor disease control without affecting disease management behaviours, and therefore the benefit of stress relief may not be related to better disease management behaviour. Therefore, it should be clarified that the purpose of this thesis is to investigate the asthma management behaviour, not the medical outcomes of asthma control.

## **2.4 Research frameworks and methodologies of the thesis**

### *Research purpose 1: Measuring asthma adherence and observing developmental change*

This chapter started with a brief discussion on the current literature on young adolescents' asthma adherence. Although there has been some evidence showing that young adolescents adhere to asthma regimes less successfully than young children, this has only been seen among chronic medication behaviours. Regarding asthma adherence as a group of behaviour in multiple dimensions (acute exacerbation behaviour, chronic medication, trigger avoidance, etc.), the Family Asthma Management System Scale (FAMSS), a family interview-based behavioural and

cognitive asthma management scale was developed recently (McQuaid et al., 2005). However, the FAMSS concerns primary behaviour and cognition of a family, whilst this current thesis aims to investigate asthma adherence as adolescent behaviour (but not family behaviour or adolescent cognition). Therefore, as progress from the idea in the FAMSS, a new instrument was developed in the first study of this thesis (chapter 3) to measure the multidimensional asthma management as adolescent behaviour, but not family behaviour or cognition. In an early adolescent sample (age 9-14), the associations between asthma adherence and age, gender or socioeconomic status were then investigated.

### *Relationships between asthma adherence and the social environment*

Soon after the discussion of asthma adherence, the social environment of a young adolescent was introduced in this chapter from the perspective of behavioural psychology. The effects of *specific social support, socio-economic status and social capital* on human behaviour were briefly summarised to address the multiple aspects of the social environment. An important feature of these social environmental factors is its context-dependency -- specific social support has to be defined specifically in relation to the behavioural context, and socioeconomic status and social capital may bring differential impacts within different contexts. Following this thought, the social environment of asthma adherence in early adolescence has to be understood before it can be clearly defined and its impact can be assessed. Therefore, the literature review led to theories from developmental psychology on the social life of a young adolescent in the 21<sup>st</sup> century shared with parents, with teachers and with peers. Many key concepts were taken from the literature to describe a supportive family or school environment. Concepts related to adults were *adult involvement* (or life-sharing), *adult warmth* (or effective communication), and *adult autonomy support* (or respect for adolescent decision making). Among peers, a warm relationship and a sense of belonging seem to be what adolescents are seeking, and *social competence* was

pointed out as a key concept in creating a supportive peer environment. Social competence among peers (or peer social competence) includes peer acceptance and social skills, among which stress-coping skills have attracted much attention in the literature.

With this knowledge from developmental psychology about a young adolescent's social life, the literature on young adolescent chronic illnesses was examined to see how much these two literatures (in developmental psychology and in chronic illnesses) are compatible. As expected, there are similarities and disparities. Although many studies support the generalisability of some theories in developmental psychology to chronic illness management behaviour, the studies in chronic illness management were generally fewer than others in the general school context. One contextual difference is the emphasis of *responsibility share* in the family environment of chronic illnesses, which is not generally an issue in other contexts. It is still not clear how family responsibility share operates in parallel with other dimensions of family relationships to support asthma adherence. Therefore, it is not only the relationships between asthma adherence and the social environment that are largely unknown in the context of adolescent chronic illnesses, but the key concepts in this context have also remained under-investigated.

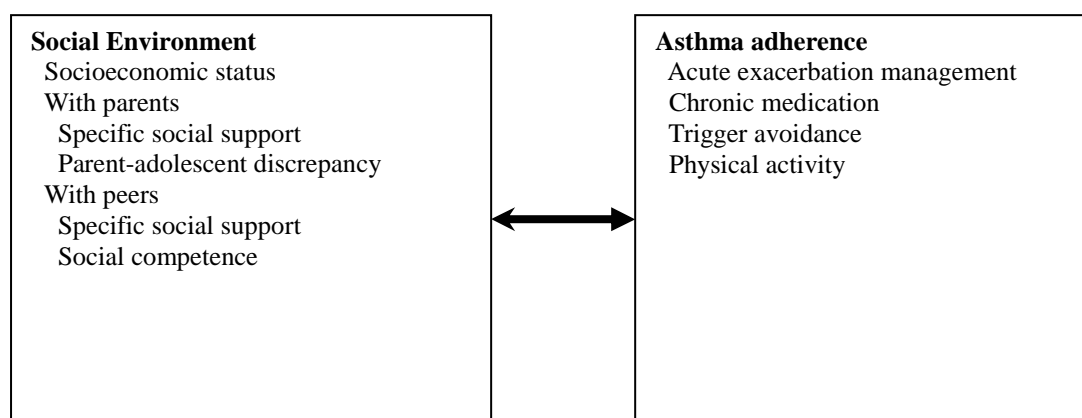
*Research purpose 2: Independent associations between asthma adherence and the social environment*

Therefore, the aim to investigate the relationship between asthma adherence and the social environment was approached in this thesis through two different research paradigms. The first approach was a quantitative approach, through which the independent associations between asthma adherence and some aspects of the social environment of early adolescence were investigated in study 2 (chapter 4). In other words, this study asked how far young adolescents' asthma adherence was influenced

by the social environment, and how greatly each dimension of the social environment explained young adolescents' asthma management behaviour. More importantly, if the young adolescents did adhere to asthma regimes less successfully when they grow older, the research asked whether or not this change could be explained by developmental changes in the social environment, and by which dimensions of developmental changes in the social environment.

As in many other studies, unfortunately, this approach has two major limitations. Firstly, it is not possible to include all aspects of the social environment in one study. Even if it was possible, social environmental factors would not be the only predictors of asthma adherence, and considering all predictors in one study would be even more difficult. For example, the fact that teacher support was not included in this study (figure 2-5) does not imply it was not important. Meanwhile, the study did not include many important psychological variables reviewed in section 2.2 (e.g. self-efficacy, attitudes, etc.). This does not exclude the possibilities of associations between asthma adherence and these psychological variables, either. However, the omission of these variables limited the study from exploring the full picture of the social environment of asthma management in early adolescence.

Figure 2-5 Post-positivist approach (covariates omitted)\*

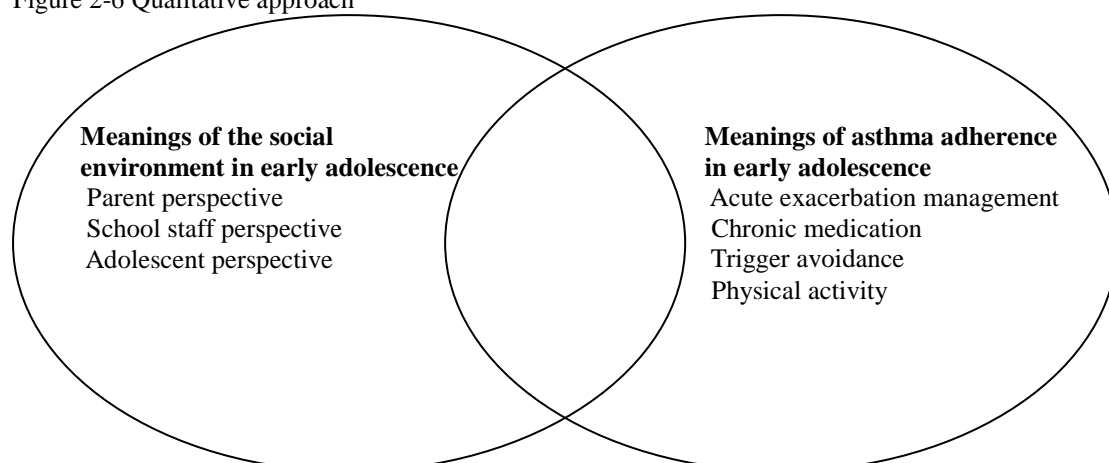


\*Covariate factors: age, gender, family structure and medication levels

*Research purpose 3: Meanings of the social environment in the context of asthma management*

The second major limitation of this quantitative approach is that a social environmental concept can only be measured when it is well-defined within a relevant context. For example, there have not been sufficient studies to provide information as to how the social environment should be defined for young adolescents with asthma. Therefore, assuming a universal meaning of the social environment in all contexts might not be appropriate, especially when the context-dependency of the impact of the social environment has been demonstrated in the literature. Therefore, a qualitative approach was adopted to explore the meanings of the social environment to adults (in study 3, chapter 5) and to adolescents (in study 4, chapter 6) within the context of asthma management. This approach aims at describing asthma management as a part of social life, or describing the contextualised meanings of asthma management. As shown in figure 2-6, therefore, the purpose of this study is to explore the overlapping area which describes the meanings of both asthma adherence and the social environment.

Figure 2-6 Qualitative approach



Although this approach seems more flexible in seeking relevant concepts in a specific context, it has the same limitation in not being able to include all perspectives. For example, the studies (study 3 and 4) only explored the perspectives

of parents, school staff and adolescents within the social environment, and therefore information on the peer environment can only be obtained from these three perspectives. Compared to the quantitative approach, however, this approach allows the flexibility to explore the social environmental concepts which have not been well-defined in the literature. Therefore, the two approaches, guided by two different research paradigms, complemented each other in supporting exploration and understanding of the relationships between asthma adherence and the social environment in early adolescence. As expected, this qualitative approach has its drawbacks – it is only possible to *address*, but not to *assess* the relationships between asthma management and the social environment. Therefore, the findings of studies will usually inform further studies, often with a quantitative approach, to assess the relationships.

#### *A brief discussion of the epistemology of a mixed-method study*

Traditional arguments on the possible dichotomy of qualitative and quantitative approaches are no longer as polarised as previously (Scheuner et al., 2008; Gucciardi et al., 2008; Creswell, 2003), and there is greater acceptance of the contribution of mixed methods. To investigate social phenomena (or a research topic), it is as important to have a panoramic view of it as to inspect it with microscope. To investigate young adolescents' asthma management, therefore, it is not sufficient only to know "*what works.*" -- "*How much it works*" and "*how it works*" are as important. "*How much it works*" provides us with the summative quantitative evaluation for an intervention, and "*how it works*" explains the qualitative mechanisms in the context, thus making the interventions more socially acceptable and feasible. Although quantitative approaches tend to reduce information to principles, and qualitative approaches tend to complicate and challenge our principles, there is no reason to believe that each approach can only be used in particular circumstances. Modern research frameworks allow us to treat this dichotomy as a spectrum of data

“structural-ness,” -- it is the data being quantitative or qualitative, not the research itself being quantitative or qualitative (Axinn and Pearce, 2006). Responding to this methodological progress, researchers’ thinking frameworks should be more flexible than being trapped into the dichotomy between “what” and “how.”

A more fundamental dichotomy in mixed (qualitative and quantitative-) method social science research is the presumption in epistemology. Questions involved in this debate are “what knowledge is,” “how to acquire knowledge,” or “what the difference between truth and knowledge is.” Traditionally, epistemologists have argued whether or not the truth can be approached objectively since most (or all) knowledge cannot stand without human beliefs. However, falling into this dichotomy does not always help researchers in practice. In the real world, one should be more pragmatic: “*truth is what works at the time*” [p.12] (Creswell, 2003). This “pragmatic approach” admits the uniqueness of the context where the knowledge is discovered (or constructed), but does not commit to any system of philosophy and reality (table 2-3).

TABLE 2-3 Epistemological claims

	<b>Brief claims</b>	<b>Mixed-method study...</b>
<b>Post-positivist</b>	Knowledge is the result of truth approached by social methods	...uses multiple methods to cross-validate the knowledge.
<b>Constructivist/ Interpretivist</b>	Knowledge is socially constructed	...provides knowledge co-constructed in multiple perspectives.
<b>Pragmatism</b>	Knowledge is what works at the time	...brings all relevant information in a research framework

This thesis adopts this pragmatic attitude to investigate the relationships between asthma adherence and the social environment in early adolescence. The “data source” included young adolescents with asthma, parents, school staff, and (arguably) the researcher’s reasoning. The data were obtained from structured questionnaires, semi-structured interviews and scenario-based interviews (discussed later). Post-positivists, behind their epistemological spectacles, would be able to interpret it as a multi-

method design (Klennert et al., 2000; Marsh et al., 2002; Renk and Phares, 2004), which helps to compensate for the loss of reliability in each part of data, and “approach the truth” in a more valid (or validatable) way. Constructivists, on the other hand, could also find their position in the study, where knowledge is a matter of interpretations of subjective experiences from multiple perspectives (Akerlind, 2005). With a pragmatic claim, the best way to investigate this topic is to understand the people, the perceptions, and the environment where this topic is relevant, and to aggregate the different kinds of knowledge into something that makes sense for the target population.

#### *Multi-informant, multi-method study*

With a pragmatic approach, different perspectives were taken into account to answer the research questions. The participants in this research, young adolescents, parents and school staff, were chosen with two overarching principles: They should be a) experienced and/or knowledgeable in the context, and b) the combination of participants should represent perspectives as comprehensive as possible on the topic of interest (Rubin and Rubin, 2005). However, the advantages and disadvantages of each type of participant are still recognised (table 2-4) -- compared to adults, young adolescents have authentic experiences in their own asthma management, but they are questionably not the most reliable source of information (Griesler et al., 2008; van Dellen et al., 2008; Burkhart et al., 2001; Poulin and Dishion, 2008). On the other hand, adults are reliable, and more capable of expressing self-reflecting thoughts. However, adults may not have experiences as authentic as the young adolescents, and they may not be aware of issues that are not observable, such as young adolescents’ private thoughts undisclosed to parents. There are also distinctions between the two kinds of adults (parents and school staff) -- compared to school staff, parents may have more in-depth knowledge of their own child. However, they may not be aware of the school aspect of young adolescents’ life as much as school staff. Their knowledge

may also be limited by the experience of their own young adolescents only. On the other hand, school staff may have the chance to compare different young adolescents, but their experiences may be limited by not knowing the details of each young adolescent's life. Therefore, a combination or comparison among the three perspectives (young adolescents, parents and school staff) provides us with a broader sense of the relationships between asthma adherence and the social environment in early adolescence.

TABLE 2-4 Advantages and disadvantages of participants

	<b>Advantages</b>	<b>Disadvantages</b>
<b>Young adolescents</b>	Experienced Aware of unobservable issues	Less "reliable"
<b>Parents</b>	In-depth knowledge Reliable	Not aware of school settings Not aware of unobservable issues (e.g. children's private thoughts undisclosed to parents)
<b>School staff</b>	Knowledgeable across different children Reliable Have been trained and more "aware" of health issues in school context	Not aware of individual child Not aware of family settings Not aware of unobservable issues

In addition, *multiple methods* were applied in this thesis to approach the three different types of participants. Compared to school staff, young adolescents and their parents are more aware of individual beliefs and behaviour, and thus structured questionnaires were completed by them to assess these individual factors quantitatively. As mature adults, parents and school staff are competent in providing independent thoughts; therefore semi-structured interviews were conducted to explore their thoughts and opinions. Finally, a scenario-based (story telling) interview was designed for young adolescents to engage in the process and to share their experiences in simulated situations (Diana, 2008; Wright et al., 2007). The details of methods are written in individual chapters.

TABLE 2-5 Advantages and disadvantages of methodological approaches

	Participants	Advantages	Disadvantages
Structured questionnaire	Parents Young adolescents	Easy to compare Time efficient	Forced choices, researcher-centred constructs
Semi-structured interview with adults	Parents School staff	Less quantitative assumptions	Difficult to compare Participant capability of providing independent and coherent information required
Scenario-based interview	Young adolescents	Interesting and easy to understand Child-centred	Difficult to compare Simulated situations may be different from “real life”

The advantages and disadvantages of different methodological approaches are summarised in table 2-5 (Creswell, 2003). Structured questionnaires are time-efficient, quantifiable methods. However, it is the most researcher-centred method -- the variables (or constructs) are defined *a priori*, and participants are forced to fit themselves into choices. Semi-structured interviews hold fewer assumptions, which allows participants to express the most relevant experiences around the topic of interest. However, the results are more flexible and more difficult to compare (than quantitative results), which complicates the interpretation of the results. Meanwhile, it requires participants to provide independent and coherent reflections, which may be more difficult for young adolescents. In scenario-based interviews for young adolescents, interviewees discussed simulated scenarios, but these might not be representative of real experiences. However, scenario-based interviews provide an agenda to discuss, and keep the interviews focusing on the agenda so that the topics can be discussed before young adolescents are tired or distracted (Caplan et al., 2005). Meanwhile, commenting on the scenarios is more interesting, and may be less stressful than disclosing their own experiences, which facilitates young adolescents to provide independent thoughts (Diana, 2008; Westcott and Kynan, 2004).

TABLE 2-6 Four studies in this research

		Participants	Approaches	Data collection
<b>Study 1</b>	Measuring asthma adherence	Young adolescents and parents (86 dyads)	Questionnaires	2007.11-2008.6
<b>Study 2</b>	Social environment and asthma adherence: associations	Young adolescents and parents (86 dyads)	Questionnaires	2007.11-2008.6
<b>Study 3</b>	Social environment and asthma adherence: the perspective of adults	School staff (n=33) and parents (n=36)	Semi-structured interviews	2007.8-2008.7
<b>Study 4</b>	Social environment and asthma adherence: the perspective of young adolescents	Young adolescents (n=34)	Scenario-based Interviews	2007.8-2008.7

Therefore, this thesis describes a multi-informant, multi-method study consisting of four studies (table 2-6) with three primary purposes

- a) To measure asthma adherence and to observe the developmental change of asthma adherence in early adolescence
- b) To investigate the independent associations between asthma adherence and the social environment in early adolescence, and
- c) To explore the meanings of the social environment within the context of asthma management in early adolescence.

By being *multi-informant*, the thesis considers different perspectives, including young adolescents with asthma, their parents and school staff. By being *multi-method*, three different approaches were used, including structured questionnaires, semi-structured interviews and scenario-based (story telling) interviews. The design undoubtedly increased the complexity of this thesis, but it was hoped that through cross-validation and cross-comparison, the authenticity of young adolescents' knowledge and the richness (and/or reliability) of adults' knowledge could complement each other.



## **Chapter 3**

### **Measuring asthma adherence (study 1)**



### **3.1 Introduction**

In this first study of the thesis, a structured questionnaire was developed to measure asthma adherence of young adolescents, and the first stage of questionnaire validation is presented in this chapter. Meanwhile, developmental changes in asthma adherence in early adolescence were investigated using this questionnaire. This adherence scale is a combination of parent- and adolescent-reported adherence. Young adolescents spend much time in the school, and a large part of their lives is not communicated to their parents. Therefore, it is important to include both parent and adolescent assessment of asthma adherence in order to evaluate the actual efficacy of medical regimes.

As mentioned in chapter 2, the asthma adherence scale developed in this study followed the Family Asthma Management System Scale (FAMSS) (McQuaid et al., 2005) in conceptualising asthma adherence as a single and multi-dimensional construct. However, compared to the Family Asthma Management System Scale, the adherence scale developed in this study concerns asthma adherence as young adolescents' actual management behaviour, and does not include their knowledge, attitudes and feelings. Meanwhile, this adherence scale concerns the young adolescents' asthma adherence, not family asthma adherence. These features allow researchers to investigate asthma adherence as adolescent behaviour, which is hypothetically subject to the influence of the social environment.

### **3.2 Participants and Methods**

#### *Parent and adolescent-reported asthma adherence scale*

The structured questionnaire included an adolescent-reported part and a parent-reported part. Young adolescents (age 9-14) reported their adherence to asthma

management regimes, while their parents reported their own assessment of young adolescents' asthma adherence. Asthma management behaviour items were derived from asthma guidelines and educational service packs designed by AsthmaUK, an asthma-specific health promotion organization in the UK. The initial 14 items included three items of acute exacerbation management (using inhalers, telling adults in asthma attacks and keeping inhalers at hand), two items of chronic management (using preventive medication and peak flow meter as required), four items of general trigger avoidance (pet and fur in bed, people with flu, smoke and air pollution, and cold weather), two items of physical activity (physical activity participation and warming up), and three items of clinical visits (showing cooperation, telling the truth and participating in discussion in clinical visits). Parents and adolescents were both asked to report their (or their children's) frequency of the 14 asthma management behaviours over the past six months on a five point Likert scale (always, usually, sometimes, occasionally, never). The questionnaire was designed in coloured written format, with Smileyfaces® to facilitate answering on the questionnaires.

Content validity was examined by two educational psychologists, two general practitioners, one mother of a child with asthma, one primary school teacher, and one secondary school teacher. They considered language appropriateness and the face validity of the items that represented young adolescents' (but not parents') asthma management. As a result, four items were deleted from the 14-item scale. These included clinical visits (3 items) that were aspects of parental asthma care, and trigger avoidance (1 item) that referred to removing pets or furry toys from bed, which did not apply to everyone. Two chronic management items did not apply to every adolescent with asthma, either. However, these two have been extensively investigated in the previous literature, and therefore it was retained in the questionnaires while additional screening questions were added for respondents to skip the question if the items did not apply to them. In the end, the remaining 10 items were used in the test of questionnaires.

In the questionnaires, adolescents and parents were asked to recall the frequencies of asthma management behaviour over the past six months. Although six months was considered a long period for young adolescents to recall, the report of asthma management behaviour did not require them to recall exact numbers or events, but to give a global assessment. Meanwhile, most young adolescents did not need to perform the management behaviours on a daily basis (i.e. using inhalers when having asthma attacks). A longer period allows them to have sufficient encounters for a general self-assessment.

### *Psychometric properties*

The psychometric properties of this questionnaire were investigated among 86 young adolescents with asthma and their parents. Invitation letters and questionnaires were sent out to young adolescents and their parents in a county of South-east England between October, 2007 and July, 2008 via teachers (n=506) in 33 schools<sup>1</sup> and physicians (n=178) in 4 general practice surgeries<sup>2</sup>. The geographic coverage of schools and general practices overlapped. Among the young adolescents, those whose parents reported that they had been diagnosed to have asthma AND had had any minor or major asthma symptoms within the past 12 months, were eligible for the study. Although there was no direct biological measure of asthma, the inclusion criteria are relatively stringent while they take participants' perceptions and asthma registers (in schools or general practices) into account.

Eligible young adolescents and their patients who agreed to participate in the study completed the *Breathe-In-Speak-out questionnaire for parents and for*

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<sup>1</sup> Parents and adolescents received invitation letters from school teachers if they had a young adolescent between the school year 5 and 9 (inclusive) who was registered in the school asthma databases.

<sup>2</sup> Alternatively, the parents could receive invitation letters from general practices if they had a young adolescent between age 10 and 14 years old, and had been prescribed with asthma preventer inhalers since January 2006 (22-30 months before the invitation).

*adolescents* respectively. This consists of asthma adherence, social support, peer social competence and socio-demographic variables. Only the asthma adherence scale and socio-demographic variables are discussed in this study, while the study methods and results related to other variables are presented in chapter 4. They completed the questionnaires anonymously and sent them back to the research team. Adolescents and parents were encouraged to complete the questionnaires independently. In June, 2008, 332 second invitation letters and questionnaires were sent out to young adolescents who had been invited by schools before April, 2008. As a result, the raw valid response rate was 13% (86 out of 684), and the adjusted response rate was estimated at 27%<sup>3</sup>.

#### *A brief discussion on the response rate*

The response rate of the study was poor when compared to school-based opt-out studies. Due to the stringent requirements of health-related ethics (see appendix for details of ethical considerations), most participants in medical studies are recruited from open advertisements (general practices, hospitals, schools, and communities), and samples are usually highly self-selected (Bender and Zhang, 2008; Morawska et al., 2008) and with small numbers such as this study (Roder et al., 2003; Penza-Clyve et al., 2004; McQuaid et al., 2003; Klinnert et al., 2000; Peeters et al., 2008; Warner et al., 2006; Newbould et al., 2007). Studies with higher response rates frequently approach pre-selected target population (e.g. patients in asthma clinics) or employ very brief questionnaires (Van Dellen et al., 2007; van Dellen et al., 2008; Lim et al., 2008; Rhee et al., 2008; Bokhour et al., 2008). There was one successful study among adolescents (age 11-18) with asthma (response rate = 95%) when participants were

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<sup>3</sup> Due to the poor reliability of school registers on current asthma (most of school-registered students with asthma are not actively asthmatic) and the anonymity of the questionnaires, it was not possible to assess the accurate response rate among eligible participants. With an estimated 20% rate within general practice-approached participants which overlapped school-approached participants, and with an estimated 50% current asthma rate within school registry (from a pilot study in a secondary school), the adjusted response rate was estimated at 27%.

approached via asthma clinics, but the response rate dropped to 31% when they were followed via mail 4 weeks later (Logan et al., 2003). In the current sample, adolescents with mild and moderate asthma in the UK do not visit special clinics, and researchers can only approach eligible participants outside the clinics, which may result in a lower response rate. These restrictions concern patients' privacy and vulnerability, but indeed bring great challenges to participant recruitment.

Another challenge in this study was related to the poor quality of school asthma register systems. Most schools only kept register of pupils having had asthma without documenting the status of asthma. Therefore, many adolescents had not had asthma symptoms for a long time. On the other hand, many schools only update the medical information annually or even only in the first year of school entry. Therefore, adolescents with newly developed asthma were not added to the registration system. Although some studies used general questionnaires for *every* student in a school (with and without asthma) to identify students with frequent wheezes (Hasnain et al., 2009; Shamsain, 2007; Gupta et al., 2004; Robertson et al., 1998), this method aims at adolescents whose asthma has not been diagnosed, and thus this is not applicable to this study of asthma management behaviour. Therefore, the external validity of a sample can only depend on its diversity, not on the similarity of variable distributions between the sample and the target population. This is not always free of benefits -- low-frequency populations (e.g. severe diseases) are sometimes over-sampled (as in this study), which might improve external validity by increasing statistical power in explaining sub-group differences. However, this study is still a small-scale, self-selected population, and generalisation of the results must be cautious.

### *Data Analysis*

To explore the psychometric property of this questionnaire, the mean level of each item was compared to one another (within-respondent comparison), and the

mean levels of each item reported by parents and by adolescents were compared (between-respondent comparison). Within-respondent and between-respondent item correlations were also investigated<sup>4</sup>. Exploratory factor analysis and confirmatory factor analysis were used to investigate the factor structure<sup>5</sup>. In selected cases, the pre-determined factor structure was compared with one-factor structure (where no underlying factor structure was assumed). Correlations between factors and factor loadings were presented. Internal consistency of summation scales was evaluated with Cronbach's alpha. For these analyses, a level of Cronbach's alpha at 0.7 or higher was considered adequate.

The percentages of missing values were examined. The treatment of missing values was decided case-by-case with theoretical reference where indicated. In general, pair-wise deletion was used in the investigation of single variable descriptive analysis, bivariate analysis and exploratory analysis. Maximal likelihood estimation was used to impute missing values in confirmatory factor analysis (on AMOS 7.0).

### **3.3 Results**

#### *Participant profiles*

The profiles of participants are summarised in table 3-1. The years of asthma history varied between 6 months and 12 years. Nearly half the parents had Bachelor

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<sup>4</sup> All questionnaire data were entered by the researcher into SPSS 15.0 (SPSS Inc. Chicago) according to written coding guidelines. The distributions and frequencies of all variables were examined. Unusual responses and missing values were double checked with the questionnaires. Variables were expressed with mean  $\pm$  standard deviation, occurrence (percentage %). Mean, quantiles and ranges were presented as required. Pearson correlation was used to investigate relationships between parametric variables. Kendall tau and Spearman rho were used for ordinal variable and non-parametric variable correlations. P values less than 0.05 were considered statistically significant.

<sup>5</sup> Exploratory factor analysis was performed with principal component analysis and with varimax rotation method. Factors with eigenvalue > 1 were extracted except where indicated. Amos 7.0 (SPSS Inc., Chicago) was used in the confirmatory factor analysis, and the fitness of pre-determined factor structure to the data was examined with criteria of satisfactory fit at root mean square error of approximation (RMSEA) < 0.08, comparative fit index (CFI) > 0.9 and non-norm fit index > 0.9.

TABLE 3-1 Participant Profiles

Age		Parent Responder	
9 years old	5 (6%)	Father only	10 (12%)
10 years old	15 (17%)	Mother only	71 (82%)
11 years old	18 (21%)	Both Parents	4 (5%)
12 years old	21 (24%)	Grandmother	1 (1%)
13 years old	12 (14%)	Not reported	0
14 years old	15 (18%)		
Not reported	0	Father's highest qualification <sup>&amp;</sup>	
		No qualification	12 (14%)
Gender		Age 16 qualification	16 (19%)
Boys	43 (50%)	Age 18 qualification	11 (13%)
girls	43 (50%)	Bachelor	16 (19%)
Not reported	0	Post-graduate	25 (30%)
		Not reported	6 (7%)
Medication <sup>#</sup>		Mother's highest qualification	
None	3 (3%)	No qualification	9 (10%)
GINA step 1	23 (27%)	Age 16 qualification	17 (20%)
GINA step 2	35 (41%)	Age 18 qualification	8 (9%)
GINA step 3	11 (13%)	Bachelor	22 (26%)
Not reported	14 (16%)	Post-graduate	24 (28%)
Time since Diagnosis	6.2±3.4 years	Not reported	6 (7%)
		Family structure (valid N=86)	
		Two parents	75 (87%)
		Single mother	9 (11%)
		Others	2 (3%)
		Not reported	0

# GINA step 1: reliever only; step 2: reliever plus low dose inhaled corticosteroid or leukotriene inhibitor; step 3, reliever plus middle dose inhaled corticosteroid or more than one preventative medication. (GINA: Global Initiation for Asthma)

&Father's educational qualification was significantly correlated with mother's educational qualification (spearman's rho=0.58, p<0.001). Mother's educational qualification was significantly higher than father's educational qualification at a marginal level of statistical significance (p=0.047, Wilcoxon Signed Ranked Test).

degrees, which is slightly higher than the county population and similar to the urban population of the county<sup>6</sup>. Meanwhile, most young adolescents had a controller medication (GINA step 2 and higher), indicating that young adolescents with less severe asthma were under-represented. Nevertheless, the sample covers a wide range of participants in terms of age, gender, medication level and parental highest

<sup>6</sup> Due to the anonymity of the questionnaires, it was not possible to locate in which area each participant resided in the county. However, compared to the estimation in 5% micro-data of British Census in 2001, the percentages of parents who had at least one degree (father 51%, mother 58%) were much higher than the estimated percentages among the COUNTY population between 30 and 39 years olds, (male 35.7%, female 33.9%), but were similar to the percentages in the URBAN area of the county between 30 and 39 years old (male 51.1%, female 51.7%).

education qualification. The distribution of family structure in this sample was uneven, and therefore, family structure was not used as a covariate in the following analysis where multivariate analysis was presented.

*Mean differences between adolescent-reported and parent-reported items*

The mean and standard deviation of individual adolescent-reported and parent-reported items of asthma management behaviours are listed in table 3-2. The rates of missing values were less than 6% except for items that were not applicable for everyone, namely item #4 (using peak flow meter as planned) and item #5 (using preventer on time). Only 48 adolescents (56%) and 46 parents (53%) reported that they had been prescribed a peak flow meter. Only 62 (72%) adolescents and 60 (70%) parents reported that they had preventive medicine.

By comparing the mean levels of reported adherence, the best performed behaviours (i.e. behaviours with best adherence) were #9 (taking part in physical activity), #10 (warming up and down thoroughly), and #1 (using inhaler when asthma attacks). The worst-performed behaviours (i.e. least adherence) were #8 (staying away from those who have a cold), #4 (using peak flow meter as planned), and #6 (taking care of self on cold days). In general, the three trigger avoidance behaviours were performed less frequently than other aspects of asthma management behaviours.

The correlations between parent and adolescent report on the same item can be seen as one indicator of parent-adolescent agreement. Each adolescent-reported asthma management behaviour was significantly correlated with the correspondent parent-reported asthma management behaviour, but the correlation coefficients were only moderate (0.28-0.59). Kendall tau correlation coefficients were seen to be highest in #3 (keeping inhaler at hand, tau=0.59), #4 (using peak flow meter as planned, tau=0.57) and #5 (using preventer on time, tau=0.52). Lowest correlation

was seen in #9 (taking part in physical activity, tau=0.28), #1 (using inhaler when asthma attacks, tau=0.39), and #6 (taking care of self on cold days, tau=0.39). In general, there was no clear pattern of these parent-adolescent correlations across different aspects of asthma management.

TABLE 3-2 Mean comparisons between adolescent-reported and parent-reported adherence

	Adolescent report		Parent report		Tau #	Parent-adolescent difference <sup>s</sup> Mean±SD
	N	Mean±SD	N	Mean±SD		
1.Using inhaler when asthma attacks	81	4.2±1.2	83	4.1±1.1	0.35*	0.0±1.3
2.Telling adults when not feeling well	86	3.9±1.0	86	4.0±1.0	0.43*	0.1±1.1
3.Keeping inhaler at hand	86	3.6±1.0	86	3.8±1.1	0.59*	0.2±0.8
4.Using peak flow meter as planned	48	2.9±1.2	46	2.8±1.3	0.57*	0.0±1.1
5.Using preventer on time	62	4.3±0.9	60	3.9±1.1	0.52*	-0.3±1.0
6.Taking care of self on cold days	86	3.0±1.3	86	3.0±1.2	0.39*	0.0±1.3
7.Staying away from pollution/smoke	86	3.6±1.3	84	3.6±1.3	0.43*	0.0±1.3
8. ...away from those who have a cold	86	2.7±1.3	85	2.1±1.2	0.43*	-0.6±1.2
9.Taking part in physical activity	86	4.9±0.4	86	4.8±0.4	0.28*	-0.1±0.5
10.Warming up and down thoroughly	85	4.3±0.8	85	4.1±0.9	0.48*	-0.3±1.0

#Kendall tau correlation coefficient between adolescent report and parent report.

\$Positive value means parent report higher adherence (frequency) than adolescents

\* p<0.05

Another indicator of parent-adolescent agreement is the differences between parent and child report on the same item. The mean parent-adolescent differences in each item were between -0.6 and +0.2. The most prominent difference was seen in #8 (staying away from those who have a cold, difference = -0.6), while mean differences of other items are within  $\pm 0.3$ . However, this does not mean that parent reports are similar to adolescent reports. Although the systemic trend of parent-adolescent difference is relatively small, the standard deviations of parent-adolescent differences were between 0.5 and 1.3. The low standard deviation of #9 (taking part in physical activity, standard deviation=0.5) can be due to the ceiling effect of the high reported scores (mean=4.8 in child report and 4.9 in parent report). The standard deviations of parent-adolescent differences in other items were around 1. Assuming a normal distribution of this parent-adolescent difference, this indicates that more than 30% of parent-adolescent differences in the items were more than 1 on the 5 point Likert

scale.

*Inter-item correlations, internal consistencies and summative adherence scale*

Due to the substantial amount of missing values in #4 and #5, they were not included in the summative score of asthma adherence, i.e. only 8 asthma management behaviours remained. Therefore, this adherence scale was not able to measure controller medication as a separate dimension of asthma adherence. This issue was discussed in the developmental process of Family Asthma Management System Scale (FAMSS) introduced earlier in this chapter, where only 53 out of the 115 children and adolescents were prescribed with controller medication; thus items related to controller medication were only applicable for those 53 children and adolescents. In FAMSS, controller medication was conceptualised as a part of (acute and chronic) medication adherence subscale, and the subscale score was the mean of all applicable items. However, this mean-assigning strategy assumed all items as random examples of medication adherence. It was not an appropriate assumption under this circumstance. Therefore, it was decided that the two items were excluded, and the chronic medical aspect of asthma adherence was not included in this adherence scale.

The Kendall tau correlation coefficient matrices among the remaining 8 asthma management behaviours are shown in table 3-3. In general, the correlation coefficients were mild to moderate between items (less than 0.44), and there was no pattern consistently observed in the correlation matrices. The internal consistency (Cronbach's alpha) of 8 adolescent-reported items was 0.618, and the internal consistency of 8 parent-reported items was 0.643. Combining the 8 adolescent-reported items and the 8 parent-reported items, the internal consistency of the combined 16-item scale (summative asthma adherence scale) was 0.783.

TABLE 3-3 Kendell tau correlation matrix of adolescent-reported and parent-reported asthma adherence items

Adolescent report	1	2	3	6	7	8	9
1.Using inhaler when asthma attacks	1						
2.Telling adults when not feeling well	0.18	1					
3.Keeping inhaler at hand	0.32*	0.39*	1				
6.Taking care of self on cold days	0.05	0.21*	0.23*	1			
7.Staying away from pollution/smoke	-0.01	0.19*	0.13	0.26*	1		
8. ...away from those who have a cold	0.15	0.12	0.08	0.26*	0.20	1	
9.Taking part in physical activity	0.07	0.06	0.06	0.10	0.11	0.00	1
10.Warming up and down thoroughly	0.01	0.12	0.15	0.21*	0.31*	0.16	0.17
Parent report	1	2	3	6	7	8	9
1.Using inhaler when asthma attacks	1						
2.Telling adults when not feeling well	0.31*	1					
3.Keeping inhaler at hand	0.39*	0.17	1				
6.Taking care of self on cold days	0.32*	0.21*	0.44*	1			
7.Staying away from pollution/smoke	0.19	0.12	0.15	0.25*	1		
8. ...away from those who have a cold	0.04	0.03	0.07	0.19*	0.25*	1	
9.Taking part in physical activity	0.20	0.01	0.07	-0.06	0.07	-0.08	1
10.Warming up and down thoroughly	0.15	0.04	0.12	0.22*	0.17	0.23*	0.22*

\* p<0.05

The satisfactory internal consistency (defined as Cronbach's alpha>0.7) of the combined scale may be due to insufficient items in separate scales, but it also supported the complementary nature of parent and adolescent report. Therefore, it was decided that the final summative adherence scale was calculated by adding values of the 16 items, with 8 items scored by parents and 8 items scored by adolescents. The 16-item summative adherence scale was also used as a measure of adherence in chapter 4. With the possible range between 16 and 80, the actual range of the scale was between 36 and 75 among this adolescent sample. The mean and the standard deviation were 59.4 and 8.4. The significance level of Kolmogorov-Smirnov test of normality was 0.10, which suggested that the deviation of the distribution of this combined scale from normal distribution was not significant. The histogram of the 16-item scale was shown in figure 3-1.

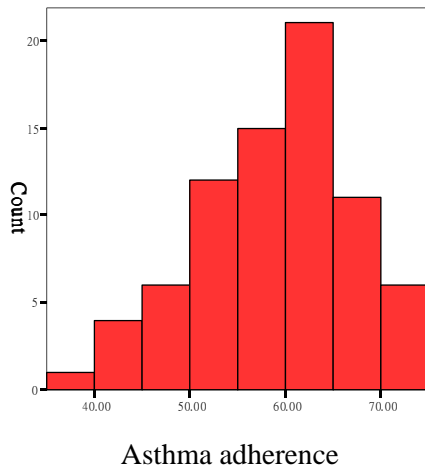


Figure 3-1 Histogram, distribution of the 16-item parent-adolescent combined adherence scale

### Exploratory factor analysis

Exploratory factor analysis was used to investigate the factor structure underlying the adherence construct with principal component analysis extraction, with varimax rotation, and with a factor extraction criteria of eigenvalue > 1.0. Three factors were extracted from the 8 adolescent-reported adherence items (table 3-4). The factor-loading pattern was consistent with the predetermined (*a priori*) factor structure. The three “trigger avoidance” items were loaded into factor 1, the three “acute exacerbation management” items were loaded into factor 2, and the two “physical activity” items were loaded into factor 3.

TABLE 3-4 Exploratory factor analysis of 8 items in asthma adherence (adolescent-reported and parent-reported)

	adolescent			Parent		
	factor 1	factor 2	factor 3	factor 1	factor 2	factor 3
1.Using inhaler when asthma attacks	-0.13	<b>0.76</b>	-0.15	<b>0.80</b>	-0.07	0.22
2.Telling adults when not feeling well	0.19	<b>0.70</b>	0.10	<b>0.60</b>	0.10	-0.02
3.Keeping inhaler at hand	0.21	<b>0.75</b>	0.26	<b>0.75</b>	0.22	0.08
6.Taking care of self on cold days	<b>0.76</b>	0.12	0.13	<b>0.58</b>	<b>0.57</b>	-0.13
7.Staying away from pollution/smoke	<b>0.65</b>	0.00	0.34	0.20	<b>0.63</b>	-0.02
8. ...away from those who have a cold	<b>0.73</b>	0.12	-0.24	-0.12	<b>0.78</b>	-0.07
9.Taking part in physical activity	-0.12	0.10	<b>0.78</b>	0.10	-0.21	<b>0.87</b>
10.Warming up and down thoroughly	0.38	0.03	<b>0.66</b>	0.06	<b>0.55</b>	<b>0.59</b>

Extraction Method: Principal Component Analysis.

Rotation Method: Varimax with Kaiser Normalization.

Correlation coefficients > 0.5 were typed in **bold**; underscores showing cross-loadings.

In the analysis of parent-reported items, there were also three factors extracted (table 3-4, right columns). Although the basic structure seemed to be consistent with the factor structure of child-reported adherence, two items were cross-loaded. Item #6 (taking care of self on cold days) was designed as a “trigger-avoidance” item, but it was also cross-loaded to the factor contributed by the three “acute exacerbation management” items (items #1-#3). Item #10 (warming up and down thoroughly) was designed as a “physical activity” item, but it was also cross-loaded to the factor contributed by the three “trigger-avoidance” items.

### *Confirmatory factor analysis*

Confirmatory factor analysis was used to compare the one-factor structure and three factor structure (figure 3-2). The three factor structure was based on the predetermined factor structure (acute exacerbation management, trigger avoidance and physical activity), which had been shown to be consistent with exploratory factor analysis of adolescent-report adherence previously in this section. The one factor structure assumed no underlying factor structure, i.e. every item was loaded to the single factor (adherence). Adolescent-reported adherence and parent-reported adherence were analysed separately. The data from all 86 parent-dyads were included, and the missing values (<1%) were imputed with maximal likelihood estimation (MLE).

Figure 3-2 One factor structure (left) and three factor structure (right) of adolescent-reported and parent-reported asthma adherence

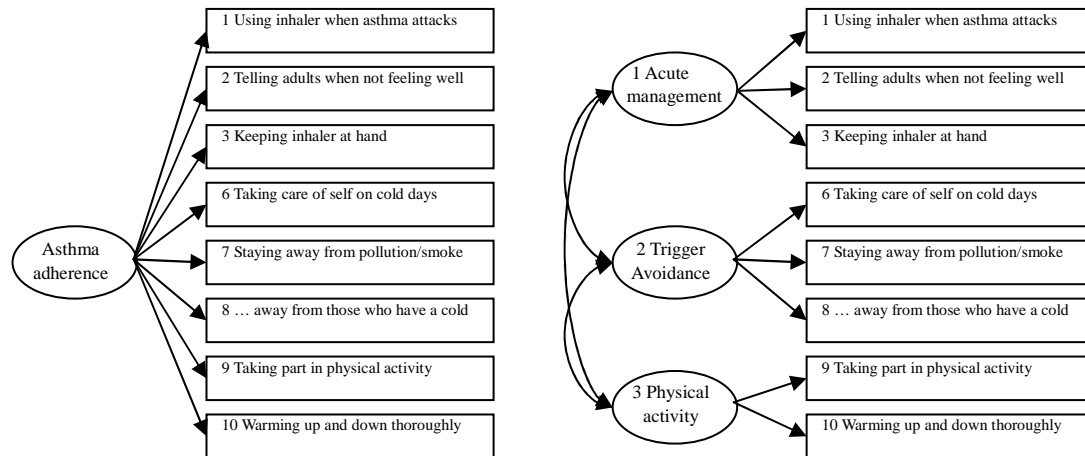


TABLE 3-5 Comparison of different assumptions in the factor structures of asthma adherence

	$\chi^2$	Df	p	RMSEA	CFI	NNFI
Adolescent 1 factor	31.90	20	0.044	0.084	0.764	0.576
Adolescent 3 factor	12.35	17	0.779	<0.001	1.000	1.195
Parent 1 factor	42.52	20	0.002	0.115	0.692	0.445
Parent 2 factor*	13.63	8	0.092	0.091	0.911	0.766

df: degree of freedom

RMSEA: Root mean square error of approximation

CFI: comparative fit index

NNFI: non-normed fit index

\*The third factor (physical activity) and its items were dropped from the three factor structure due to lack in variability

The comparisons of fit indices are shown in table 3-5. The one factor structure did not fit the adolescent-reported data and the parent-reported data to the satisfactory level (RMSEA>0.8, CFI<0.9, NNFI<0.9). By contrast, the three factor structure satisfactorily fit the adolescent-reported data (RMSEA<0.001, CFI=1.000, NNFI=1.195). On the other hand, when the parent-reported data was used, the estimation of the parameters in the three factor structure was not successful -- the model was under-specified because of the lack of variability in the third factor (physical activity). When the third factor was dropped from the model (along with the two items associated with the factor), the fitness of the remaining two-factor structure improved substantially, although still not satisfactory to all fitness criteria

(RMSEA=0.091, CFI=0.911, NNFI=0.766). Therefore, both exploratory and confirmatory factor indicated that adolescent-reported adherence scale has a clearer three-factor structure than parent-reported adherence scale, and the three-factor structure was identical to the pre-determined factor structure.

TABLE 3-6 Correlation matrix of three latent factors in adolescent-reported asthma adherence

Factor	1	2	3
1 acute exacerbation management	1		
2 trigger avoidance	0.43	1	
3 physical activity	0.28	0.56	1

TABLE 3-7 Regression weights of three latent factors on 8 observed items in adolescent-reported asthma adherence (3 factor structure)

	Standardised regression weights		
	factor 1	2	3
1.Using inhaler when asthma attacks	0.38		
2.Telling adults when not feeling well	0.52		
3.Keeping inhaler at hand	0.85		
6.Taking care of self on cold days		0.65	
7.Staying away from pollution/smoke		0.57	
8. ...away from those who have a cold		0.45	
9.Taking part in physical activity			0.28
10.Warming up and down thoroughly			0.82

Factor 1: acute exacerbation management; Factor 2: trigger avoidance; Factor 3: physical activity  
 $\chi^2=12.35$  (df=17, p=0.779), RMSEA<0.01, CFI=1.000, NNFI=1.195

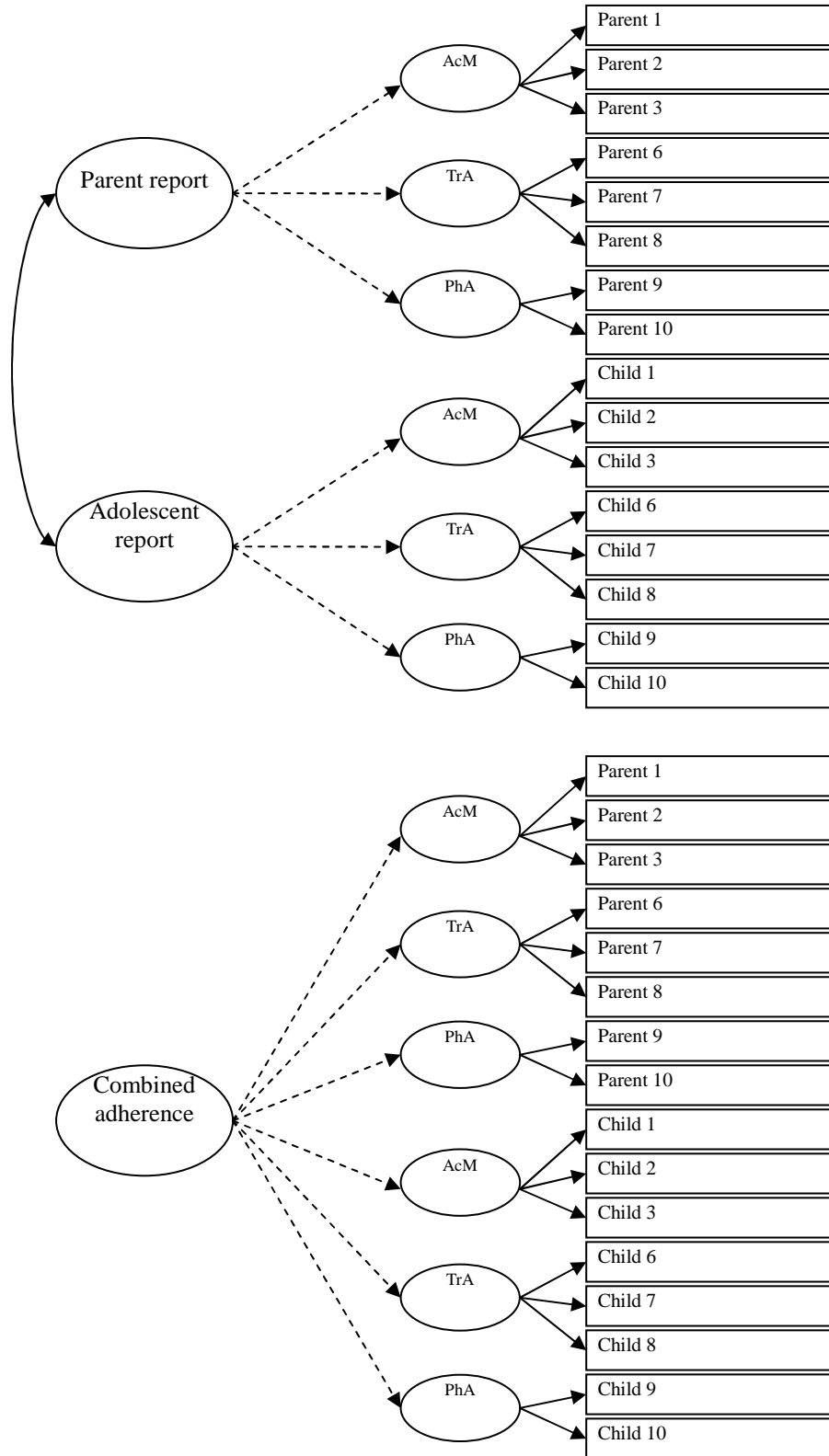
In the 3-factor structure, the estimation of latent factor correlation and the regression weight of three latent factors on 8 adolescent-reported adherence items were shown in table 3-6 and 3-7. The three latent factors were mildly to moderately correlated with one another (r=0.28~0.56). The regression weights were more evenly distributed in trigger avoidance behaviours (weight between 0.45 and 0.65) than in the other two factors, where factor 1 (acute exacerbation management) was heavily loaded on item #3 (keeping inhaler at hand), and factor 3 (physical activity) was heavily loaded on item #10 (warming up and down thoroughly).

*Further confirmatory factor analysis for parent-adolescent factor consistency*

Further analysis was conducted to investigate the factor structures of adherence. In the previous section, it was shown that both parent and adolescent reports to some degree yielded similar factor structures, and the structure also matched the a priori structure. Earlier analysis also showed that parent- and adolescent- reported correspondent items were moderately correlated. In order to provide more in-depth quantitative evidence to compare the factor structures, further confirmatory factor analysis was conducted with two assumed multi-level factor structure. A two-adherence-construct factor structure (figure 3-3) tested the similarity between factor structures underlying parent-reported adherence and child-reported adherence, and a one-adherence-construct factor table (figure 3-3), tested the fitness (or appropriateness) to consider the two constructs as one, the adherence with “combined perspectives.”

Assumptions were made in the following order: firstly, the correlated uniqueness (CU) of each item was tested. Correlated uniqueness assumes that there were correlations underlying the structure of items. Because the parent questionnaires and child questionnaires were worded in parallel, it was reasonable to assume that item 1 responses from parents would be correlated with item 1 response from adolescents, that item 2 responses from parents would be correlated with item 2 response from adolescents, and so on. Secondly, consistent first level factor loading (FL1) were assumed in the existence of (or on top of) the assumption in correlated uniqueness. This model tested whether or not the factor loadings at the first level of the structure (the global adherence loaded on the three subcategories, namely acute

Figure 3-3 Two adherence (top) and one adherence (bottom) factor structures, further investigation of factor structures in asthma adherence between parent and child reports



AcM: acute exacerbation management; TrA: trigger avoidance; PhA: physical activity  
 Dashed arrows: first level factor loadings; solid arrows: second level factor loadings

exacerbation management, trigger avoidance and physical activity) were consistent between parent reports and adolescent reports. Finally, consistent second level factor loadings (FL2) were assumed and tested in the existence of the assumptions in correlated uniqueness and consistent first level factor loadings.

The results are shown in table 3-8. In both factor structures (2-adherence and 1-adherence construct factor structures), assuming correlated uniqueness substantially improved the goodness of model fit. Furthermore, assuming consistent factor loadings at level 1 and level 2 did not jeopardise the model fit, suggesting that the factor structure of adherence was consistent across informants (parents and adolescents). Meanwhile, the correlation between parent-reported adherence and adolescent-reported adherence was 0.932, and the goodness of fit indices of 1-adherence construct factor structures was comparable with the indices of 2-adherence construct factor structure. Therefore, this evidence suggests a consistent factor structure between parent-reported and adolescent-reported adherence, regardless of the relatively unclear factor structure in parent-reported adherence demonstrated in earlier sections.

TABLE 3-8 Comparison of different assumptions in the factor structures of asthma adherence

	$\chi^2$	df	p	RMSEA	CFI	NNFI
2 adherence constructs						
Null (no assumption)	208.43	97	<0.001	0.116	0.605	0.447
CU	108.18	89	0.082	0.050	0.932	0.896
CU, FL1	108.81	91	0.098	0.048	0.937	0.906
CU, FL1, FL2	115.51	96	0.085	0.049	0.931	0.902
1 adherence construct						
Null (no assumption)	210.95	98	<0.001	0.116	0.600	0.445
CU	108.56	90	0.089	0.049	0.934	0.901
CU, FL1	111.98	93	0.088	0.049	0.933	0.902
CU, FL1, FL2	117.27	98	0.090	0.048	0.932	0.905

CU: correlated uniquenesses in all 8 items

FL1: equal factor loadings at first level (adherence on acute exacerbation management, adherence on trigger avoidance, and adherence on physical activity)

FL2: equal factor loadings at second level (acute exacerbation management, trigger avoidance and physical activity on their manifest items)

*Correlation of subscales and combined adherence scales*

As shown in table 3-9, each adolescent-reported subscale, calculated as the non-weighted sum of all contributory items in the subscale, was significantly correlated with the corresponding parent-reported subscale ( $\rho > 0.5$ ), and the summative adolescent-reported adherence scale was significantly correlated with the summative parent-reported adherence scale ( $\rho = 0.62$ ). However, the correlation coefficients between subscales were not all significant. Specifically, adolescent-reported physical activity was not significantly correlated with adolescent-reported acute exacerbation management, and parent-reported physical activity was not significantly correlated with parent-reported acute exacerbation management and parent-reported trigger avoidance. Nevertheless, the parent-reported and adolescent reported summative scales were both significantly correlated with the subscales that contributed to it, and the parent-adolescent combined 16 item adherence scale was significantly correlated with all subscales that contributed to it. In other words, this result clearly shows the degree of consistency between parent and adolescent concurrent report, as well as the degree of differentiations among adherence subscales.

TABLE 3-9 Spearman correlation of subscales

		1	2	3	4	5	6	7	8
Adolescent	Acute <sup>1</sup>								
	Trigger <sup>2</sup>	.26*							
	Physical <sup>3</sup>	.14	.28*						
	Total <sup>4</sup>	.72*	.82*	.41*					
Parent	Acute <sup>5</sup>	.55*	.20	.16	.46*				
	Trigger <sup>6</sup>	.36*	.57*	.19	.58*	.36*			
	Physical <sup>7</sup>	.29*	.09	.50*	.29*	.15	.20		
	Total <sup>8</sup>	.57*	.43*	.29*	.62*	.79*	.80*	.42*	
Combined	9	.69*	.67*	.38*	.87*	.70*	.77*	.38*	.91*

\* $p < 0.05$

*Correlations between adherence scales and demographic factors or medication level*

In terms of subscales (table 3-10), older age was correlated with poorer adolescent-

reported trigger avoidance and physical activity behaviour, but there was no correlation between age and adolescent-reported acute exacerbation management and all three parent-reported subscales. This may indicate the increase of self-reported bias with age in trigger avoidance and physical activity (DuBois and Silverthorn, 2004a; Rhee et al., 2008), but the possibility that parents were unaware of their children's non-adherence to the two types of asthma management behaviour cannot be excluded. Gender, on the other hand, had no association with any aspect of asthma adherence.

TABLE 3-10 Spearman correlation between subscales and age, gender, parent education qualification and medication

		Age	Gender <sup>#</sup>	Father's highest qualification	Mother's highest qualification	Medication
Adolescent	Acute	-.19	.01	.13	-.09	.36*
	Trigger	-.35*	.09	-.22*	-.07	.12.
	Physical	-.30*	.02	-.12	-.04	-.04
	Total	-.37*	.04	-.03	-.07	.28*
Parent	Acute	-.14	.08	-.10	-.14	.30*
	Trigger	-.12	.20	-.15	-.22*	.25*
	Physical	-.10	-.11	-.14	-.23*	.02
	Total	-.16	.14	-.05	-.25*	.33*
Combined		-.30*	.10	-.03	-.17	.34*

# boys=1, girls=2

\*p<0.05

Interestingly, compared to the associations between age and *adolescent-reported* trigger avoidance or physical activity, higher maternal educational qualification was significantly correlated with poorer *parent-reported* trigger avoidance and physical activity, but not with parent-reported acute exacerbation and all aspects of adolescent-reported asthma adherence subscales. Higher paternal highest education qualification, however, was only correlated with poorer adolescent-reported trigger-avoidance behaviour, but not with all other aspects of parent-reported or adolescent-reported adherence. Most parent participants were mothers, and the negative correlation between two aspects of parent-reported asthma adherence (trigger avoidance and physical activity) and maternal education (but not paternal education) might reflect report bias more than the actual relationships between parent education and asthma

adherence. However, there is no evidence in this study to confirm this point.

Medication level was the only variable that was associated with acute exacerbation management. Compared to age and parental education which tend to be associated with trigger avoidance and physical activity, higher adolescents' medication level was correlated with higher adherence scales in both parent-reported and adolescent-reported acute exacerbation management. The relationships between asthma severity and adherence to controller medication are controversial in the literature, and there are no studies that specifically investigate acute exacerbation management (van Dellen et al., 2008; McQuaid et al., 2003). Whether this association reflects adolescents' actual behaviour pattern or report bias requires further studies to investigate.

In terms of the summative adherence scales, higher adolescent-reported summative adherence was significantly correlated with younger age and higher medication level, but not with gender or parental educational qualification. Higher parent-reported adherence was significantly correlated with lower mother's educational qualification and higher medication level. These are all consistent with previous findings in subscales. Finally, the combined 16-item scale was correlated with age and medication level, but not with gender or parental educational qualifications. Therefore, adherence tended to be lower (or reported lower) among older adolescents and those with milder asthma.

### **3.4 Summary and Conclusion**

An asthma adherence scale completed by parents and adolescents is developed in this study. To the knowledge of the writer, this is the first behavioural scale that measures multiple aspects of asthma adherence behaviour. A three-factor structure (acute exacerbation management, trigger avoidance, and physical activity) was

supported by factor analysis, and this factor structure seems to be consistent between parents and adolescents. Another important feature of this scale is that the combination of parent report and adolescent report achieves a satisfactory reliability (Cronbach's alpha 0.78). Therefore, this brief and reliable 16-item scale represents a summative assessment of a heterogeneous collection of asthma management behaviours.

Using this asthma adherence scale, the declining age trend is demonstrated in early adolescence, confirming previous studies in asthma controller medications and diabetes management (McQuaid et al., 2003; Dashiff et al., 2009). Subscale analysis indicated that this decline may be attributed to lower values in adolescent-reported items of trigger avoidance and physical activity. However, it is not possible to differentiate between age-related behavioural difference and age-related report bias. Further studies (e.g. concurrent validity) will be required to confirm this finding.

As discussed earlier (section 3.2), this study is limited by the small sample size, and the suboptimal response rate impaired the sample representativeness. Although parents and adolescents were encouraged to complete the questionnaires separately, the independence of respondents was not guaranteed, and the effect of social desirability cannot be eliminated. Besides the comparison between parent and adolescent reports, there was no other measure to demonstrate the concurrent validity of the questionnaires. Despite the satisfactory internal consistency of the combined adherence scale, summative integration of multiple aspects of school asthma care remains difficult to interpret.

Nevertheless, this is a brief, cheap and reliable assessment of school asthma adherence for early adolescence. Because it concerns young adolescents' personal asthma adherence behaviour, it is potential for assessing future interventions that aim to improve asthma care in early adolescence.

**Chapter 4**  
**Social environment and asthma adherence:**  
**Associations (Study 2)**



## 4.1 Introduction

In study 1 (chapter 3), an asthma adherence scale for early adolescence was developed, and a negative association was found between age and asthma adherence (age 9-14). In this chapter, an associative (cross-sectional) study was presented, and the family and the peer social environment of early adolescence was investigated to explain which aspect of the social environment was accounted for the developmental change in asthma adherence. The literature has been reviewed in chapter 2 to develop research questions in this study. Firstly, theories from behavioural psychology have shown great impacts of specific social support on human behaviour, and theories from developmental psychology have identified adults and peers as two important sources of social support. Therefore, the associations of asthma management with asthma-specific parent support and asthma-specific peer support were compared in this study. Secondly, unlike in adult-adolescent relationships where adolescents usually receive support from adults, adolescents in peer relationships are also expected to adopt social skills in order to create a supportive peer environment. Therefore, some aspects of social competence among peers were investigated in this study as a special interest, in which adolescents' peer stress-coping activities and peer acceptance were used to explain asthma adherence. It was also hypothesised that social competence might be a *resilience factor* for asthma management. Resilience (in educational psychology) refers to a dynamic process encompassing positive adaptation within the context of significant adversity (Luthar et al., 2000), or the capacity for resistance to the negative influence of an adverse environment. Social competence has been increasingly investigated as a key resilience factor during childhood and early adolescence for higher school achievement and fewer behavioural problems (Niles et al., 2008; Luthar et al., 2000; Niles et al., 2006; Gardner et al., 2008). Following this knowledge, this study aims to explore whether or not the benefits of social competence as a resilience factor can be generalised to young adolescents with asthma.

Finally, following the results in chapter 3 and in the literature, it seems that young adolescents do find it difficult to adhere to asthma regimes when they are older. After exploring the independent associations between asthma adherence and social environmental factors, this study asks whether or not this age-related adherence decline can be explained by these social environmental factors. Although there are still many other aspects of the social environment remaining un-explored in this study, many of them are explored qualitatively in study 3 and 4 (chapter 5 and 6) to increase our knowledge and understanding of the social environment in the context of young adolescents' asthma management.

## **4.2 Participants and methods**

This is a (cross-sectional) survey. The data were obtained from the Breathe-In-Speak-Out questionnaire (described below) completed by 86 young adolescents and their parents as explained in chapter 3. The recruited sample had a similar level of education to the urban population, but a higher level of education than the county population from which they were drawn. The sample also had more severe asthma medications than the general population. Nevertheless, the sample included young people of different ages, both genders, and a range of parental highest education levels and medication levels.

### *Breathe-In-Speak-Out questionnaire*

The Breathe-In-Speak-Out questionnaire was a structured questionnaire which included an adolescent-report questionnaire and a parent-report questionnaire (table 4-1 and appendix). The adolescent-report questionnaire included items on asthma symptom frequencies, self-reported adherence, asthma-specific peer support, peer acceptance and peer-related coping activities. The parent-report questionnaire

included items on parent-reported adolescent adherence, asthma-specific parent support, peer acceptance and background variables, including symptom frequency, medications and demographic characteristics.

TABLE 4-1 Contents of the Breathe-In-Speak-Out Questionnaire (parent and adolescent)

Instruments and main constructs (references)	Dimensions of constructs
<b>A. Adolescent questionnaire</b>	
Adherence (8 items) British guideline on the management of asthma (BTC, 2005), Global initiative of asthma (GINA, 2005)	Acute exacerbation management (3 items); Trigger avoidance (3 items); Physical activity management (2 items)
Asthma-specific peer support (8 items) (Ajzen, 1991)	
Social competence (22 items) (Pretzlik, 1997; Harter, 1982; Spirito et al., 1991)	Coping Activities (15 items); Peer acceptance (7 items)
Asthma severity (GINA, 2005)	Symptom frequency (2 items)
<b>B. Parent-report questionnaire</b>	
Demographic characteristics	Age, gender, family structure, parent educational status (1 item each)
Asthma severity (GINA, 2005)	Symptom frequency (2 items); Current medications (open questions)
Parent-report adolescent adherence (8 items) Asthma-specific parent support (8 items)	Derived from adolescent-reported adherence Derived from adolescent-reported questionnaire
Parent-reported adolescent peer acceptance (among peers) (7 items)	Derived from adolescent-reported peer acceptance

Among the variables, asthma-specific peer support and asthma-specific parent support were two aspects of specific social support, while coping activities and peer acceptance were two aspects of social competence among peers. The details of background variables and the properties of asthma adherence<sup>7</sup> have been described in

<sup>7</sup> Briefly, the *asthma adherence scale* was a 16 item questionnaire where parents and adolescents were asked separately for the frequency of 8 asthma management behaviours (table 4-2) the adolescent performed over the past 6 months in acute exacerbation management (3 items), trigger avoidance (3 items) and physical activity (2 items) on a 5 point Likert scale (always, usually, sometimes, occasionally, never). The internal consistency (Cronbach's alpha) of this parent-adolescent combined asthma adherence scale was 0.783

chapter 3. Therefore, only the psychometric properties of other social environmental factors will be demonstrated in this chapter (see section 4.3). A trial on-line questionnaire was piloted with the goal of enhancing the response rate. This was not successful, perhaps due to the lack of immediate and quick access to the Internet at the time potential participants received research invitation. In the end, the questionnaire was designed in a coloured written format, with authorization to use Smileyfaces® to decorate the questionnaires.

TABLE 4-2 Asthma adherence behaviours included in Breathe-in-Speak-out questionnaire

Dimensions	Items
Drug adherence	1 Use inhaler when having an asthma attack
	2 Tell adults when not feeling well
	3 Keep inhaler at hand
Trigger avoidance	4 Take care of self on cold/windy days (wear a scarf, take a puff of inhaler)
	5 Avoid air pollution or areas where people smoke
	6 Try to stay away from others who have a cold
Exercise management	7 Take part in physical activity when asthma is well controlled
	8 Warm up and down thoroughly during exercise

The length of the questionnaires was one of the major concerns when designing the questionnaire for adolescents. A 30 minute questionnaire with adolescent-reported self-efficacy, attitudes towards behaviour and parent support was tested in a pilot study. However, the length and the repetitiveness (on asthma management) of the questionnaire appeared to discourage adolescents from completing the questionnaire. These items were therefore deleted from the questionnaires, and only the social environmental variables were included in the final version. Because adolescents' own attitudes and beliefs were not measured in this questionnaire, it was possible that the correlations of asthma-specific peer support (or parent support) and adherence behaviours is mediated, moderated, or confounded by the effect of adolescents' own attitudes or beliefs. However, the detail of psychological mechanisms is beyond the scope of this research. The final questionnaire took 10-15 minutes for each (parent

and adolescent) to complete.

### **4.3 Measurement properties of social environmental variables**

This section presents the social environmental variables included in the Breathe-in-Speak-out questionnaire and some measurement properties of these variables. They are asthma-specific parent support, asthma-specific peer support, coping activities and peer acceptance. Data management was similar to that described in chapter 3. Mean differences and correlations between items were examined. Exploratory factor analysis and confirmatory factor analysis were used to investigate the factor structure underlying asthma-specific peer support and asthma-specific parent support. The fitness of the pre-determined factor structures to the data was examined with criteria of satisfactory fit at root mean square error of approximation (RMSEA) < 0.08, comparative fit index (CFI) > 0.9 and non-norm fit index > 0.9. Cronbach's alpha was used for the internal consistencies of each variable, and a value > 0.7 was considered acceptable.

#### **Specific social support: asthma-specific peer support and parent support**

*Asthma-specific social support* is defined as how much significant others (peers or parents) support adolescents specifically in asthma management. In order to explore asthma-specific peer support, *adolescents* were asked to complete an 8-item questionnaire which asked how their friends felt about 8 asthma management behaviours on a five point numbered Likert scale (5 as good and 1 as bad, 3 as a neutral attitude). Asthma-specific parent support was explored through an 8-item questionnaire where *parents* were asked how often they helped or encouraged these adolescents in the 8 asthma management behaviours on a five point Likert scale (always, usually, sometimes, occasionally, never).

### *Mean differences*

List-wise deletion was used in the analysis of this section. Among 86 parent-adolescent dyads, 83 dyads had fully completed data on (adolescent-reported) peer support and (parent-reported) parent support of asthma management. The descriptive analysis of individual items is shown in table 4-3. To compare the means among different items, adolescents reported more peer support in acute exacerbation management behaviours (#1, #2, #3) and physical activity behaviours (#7, #8) than in trigger avoidance behaviours (#4, #5, #6). A similar pattern was seen in parent-reported parental support, except for a slightly lower value in #8 (warming up and down thoroughly). When asthma-specific peer support and parent support were compared item-by-item (with Wilcoxon Signed Ranks Test), there were significant differences in three behaviours (#6, #7, #8). Peer support was higher than parent support in #6 (staying away from pollution and people who smoke) and #8 (warming up and down thoroughly), and peer support was lower than parent support in #7 (taking part in physical activity). In general, these results suggest that parents and peers are more supportive in acute exacerbation management and physical activity than in trigger avoidance, and the discrepancy between parent support and peer support is more prominent in physical activity than the other 2 aspects of asthma management.

TABLE 4-3 Mean comparisons between asthma-specific peer support and parent support

	Peer support		Parent support		P value#
	N	Mean±SD	N	Mean±SD	
<b>Acute exacerbation management</b>					
1.Using inhaler when asthma attacks	83	4.4±0.9	83	4.2±1.1	0.34
2.Telling adults when not feeling well	83	4.2±0.9	83	4.4±1.0	0.11
3.Keeping inhaler at hand	83	4.1±1.0	83	4.2±1.1	0.38
<b>Trigger Avoidance</b>					
4.Taking care of self on cold days	83	3.6±1.0	83	3.8±1.1	0.20
5.Staying away from pollution/smoke	83	3.9±1.1	83	3.7±1.2	0.12
6.Staying away from who has cold	83	3.1±1.0	83	2.6±1.4	0.002
<b>Physical activity</b>					
7.Taking part in physical activity	83	4.4±0.9	83	4.8±0.5	<0.001
8.Warming up and down thoroughly	83	4.1±0.9	83	3.7±1.4	0.002

# Wilcoxon Signed Ranks Test

\*p<0.05

TABLE 4-4 Inter-item correlation matrix of asthma specific peer support

Asthma-specific peer support	1	2	3	6	7	8	9
<b>Acute exacerbation management</b>							
1.Using inhaler when asthma attacks	1						
2.Telling adults when not feeling well	<b>0.</b>	1					
3.Keeping inhaler at hand	<b>0.54</b>	<b>0.4</b>	1				
<b>Trigger avoidance</b>							
4.Taking care of self on cold days	0.	0.41	0.44	1			
5.Staying away from pollution/smoke	0.1	0.27	0.6	<b>0.5</b>	1		
6.... away from those who have a cold	0.0	0.1	0.11	<b>0.44</b>	<b>0.20</b>	1	
<b>Physical activity</b>							
7.Taking part in physical activity	0.06	0.10	0.21	0.26	0.7	0.0	1
8.Warming up and down thoroughly	0.15	0.12	0.1	0.6	0.0	0.1	<b>0.4</b>

\* p<0.05. Intra-factor correlation was shown in **bold**

TABLE 4-5 Inter-item correlation matrix of asthma-specific parent support

Parent-reported parent support	1	2	3	6	7	8	9
<b>Acute exacerbation management</b>							
1.Using inhaler when asthma attacks	1						
2.Telling adults when not feeling well	<b>0.</b>	1					
3.Keeping inhaler at hand	<b>0.4</b>	<b>0.4</b>	1				
<b>Trigger avoidance</b>							
4.Taking care of self on cold days	0.	0.1	0.1	1			
5.Staying away from pollution/smoke	0.1	0.0	0.12	<b>0.6</b>	1		
6.... away from those who have a cold	0.0	0.2	0.22	<b>0.</b>	<b>0.5</b>	1	
<b>Physical activity</b>							
7.Taking part in physical activity	0.06	0.16	0.10	-0.0	0.07	-0.04	1
8.Warming up and down thoroughly	0.15	0.1	0.1	0.2	0.21	0.11	<b>0.0</b>

\* p<0.05

Intra-factor correlation was shown in **bold**

### *Inter-item correlations and internal consistencies*

The correlation matrix of eight adolescent-reported asthma-specific peer support items is shown in table 4-4. Most items were significantly correlated with one another. The correlation coefficients within three pre-determined factors (acute exacerbation management, trigger avoidance, physical activity) were all significant, but not necessarily higher than inter-factor correlation coefficients. The internal consistency (Cronbach's alpha) of the 8 items was 0.81. On the other hand, the correlation matrix of eight asthma-specific parent support items is shown in table 4-5. The correlation coefficients within three pre-determined factors (acute exacerbation management, trigger avoidance, physical activity) were all significant, and tended to be higher than inter-factor correlation coefficients. The internal consistency (Cronbach's alpha) of the 8 items was 0.72. Simply to conclude from the raw correlation coefficients between items, it seems the asthma-specific parent support scale has a clearer three-factor structure than the asthma-specific peer support scale.

### *Exploratory factor analysis*

The results of exploratory factor analysis of asthma-specific peer support and parents support are shown in table 4-6. With principle component analysis extraction, varimax rotation and the extraction criteria of eigenvalue>1, three factors were extracted from both peer support and parent support. The factor structure underlying peer support was inconsistent with the pre-determined factor structure. Instead of being aligned with the other two trigger avoidance behaviours, #5 (staying away from pollution or where people smoke) was correlated with the two physical activity behaviours (#7 and #8). Nevertheless, the correlation coefficient between #5 and factor 3 (the factor that was highly correlated with the other two trigger avoidance behaviours) was 0.39, not much lower than the correlation coefficient between #7 and factor 2 ( $r=0.52$ ).

TABLE 4-6 Exploratory factor analysis of 8 items in asthma-specific peer support and parent support

	Peer			Parent		
	factor 1	factor 2	factor 3	factor 1	factor 2	factor 3
<b>Acute exacerbation management</b>						
1.Using inhaler when asthma attacks	<b>0.72</b>	0.38	-0.04	<b>0.86</b>	0.09	0.04
2.Telling adults when not feeling well	<b>0.83</b>	-0.10	0.24	<b>0.73</b>	0.21	0.17
3.Keeping inhaler at hand	<b>0.80</b>	0.22	0.10	<b>0.85</b>	0.15	0.02
<b>Trigger Avoidance</b>						
4.Taking care of self on cold days	0.41	0.35	<b>0.69</b>	0.33	<b>0.64</b>	0.09
5.Staying away from pollution/smoke	0.39	<b>0.52</b>	0.39	0.06	<b>0.78</b>	0.19
6.... away from those who have a cold	0.01	0.07	<b>0.92</b>	0.13	<b>0.81</b>	-0.11
<b>Physical activity</b>						
7.Taking part in physical activity	0.06	<b>0.85</b>	0.09	0.10	-0.12	<b>0.83</b>
8.Warming up and down thoroughly	0.13	<b>0.74</b>	0.14	0.07	0.28	<b>0.75</b>

Extraction Method: Principal Component Analysis.  
 Rotation Method: Varimax with Kaiser Normalization.  
 Correlation coefficient > 0.5 were typed in **bold**

In contrast to peer support, parent support revealed a clearer factor structure as expected. Three factors were extracted, and the correlation structure was consistent with the pre-determined factor structure (acute exacerbation management with #1, #2 and #3, trigger avoidance with #4, #5 and #6, and physical activity with #7 and #8). Meanwhile, the three factors were discriminated from one other in a clear pattern. Therefore, the result of exploratory factor analysis seems to agree that asthma-specific parent support has a clearer three-factor structure than asthma-specific peer support.

#### *Confirmatory factor analysis*

In the confirmatory factor analysis of parent support, the one-factor structure (where all items were loaded into a single factor, see figure 4-1 left) was compared to the pre-determined three-factor structure (see figure 4-1, right above), which was also consistent with exploratory factor analysis. The model fitness was compared in table 4-7. The one-factor structure did not satisfactorily fit the data (RMSEA=0.12, CFI=0.81, NNFI=0.65), and the three-factor structure fit the data very satisfactorily (RMSEA<0.001, CFI=1.00, NNFI=1.05).

Figure 4-1 Three types of factor structures in asthma-specific parent and peer support scales

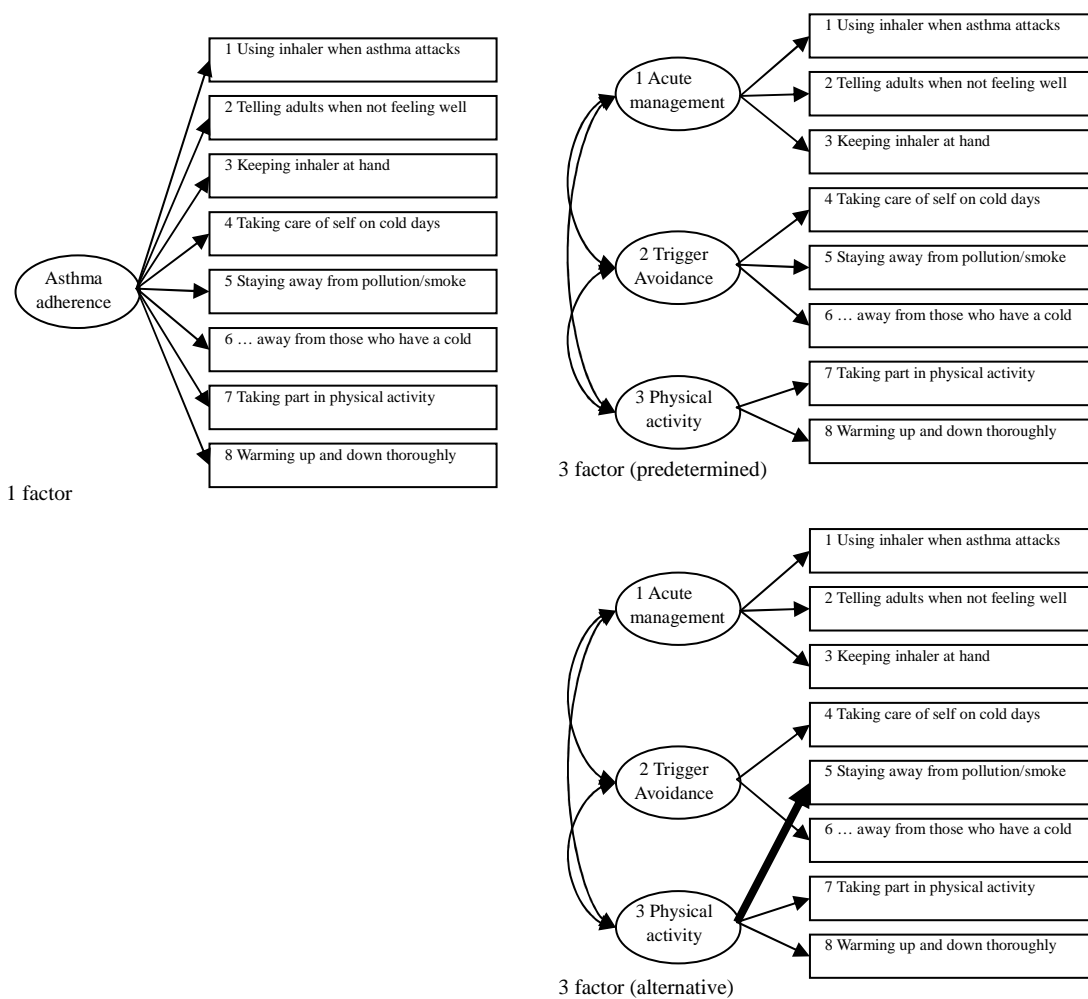


TABLE 4-7 Comparisons of different assumptions in the factor structures of asthma-specific parent support

	$\chi^2$	df	p	RMSEA	CFI	NNFI
1 factor	42.44	20	0.002	0.12	0.81	0.65
3 factor (pre-determined) #	14.40	17	0.638	<0.001	1.00	1.05

df: degree of freedom

RMSEA: Root mean square error of approximation

CFI: comparative fit index

NNFI: non-normed fit index

#the pre-determined model (#1, #2 and #3 with acute exacerbation management, #4, #5 and #6 with trigger avoidance, and #7, #8 with physical activity)

In the confirmatory factor analysis of peer support, the fitness of the one factor model, the three-factor pre-determined model and the three-factor alternative model were compared (figure 4-1). The three-factor *pre-determined* model was consistent with the model used in adherence behaviour, and the three-factor *alternative* model was derived from exploratory factor analysis earlier in this section, where #7 (staying away from air pollution or area where people smoke) was loaded more to physical activity than to trigger avoidance. The results (table 4-8) showed that both three-factor structures fit the data better than the one factor structure. The fit indices (RMSEA, CFI and NNFI) of the two types of three-factor structures (predetermined and alternative) were very close. The values of RMSEA and NNFI were both non-satisfactory (both RMSEAs>0.08 and NNFI<0.9), and the values of CFI were both borderline satisfactory (both CFIs<0.9). Although the three-factor alternative structure was favourable in exploratory factor analysis, the confirmatory analysis suggests that the pre-determined factor structure fit the data as well as (or slightly better than) the alternative factor structure.

TABLE 4-8 Comparison of different assumptions in the factor structures of asthma-specific peer support

	$\chi^2$	df	p	RMSEA	CFI	NNFI
1 factor	56.65	20	<0.001	0.15	0.79	0.63
3 factor (pre-determined)#	32.28	17	0.014	0.10	0.91	0.82
3 factor (alternative)#	33.76	17	0.009	0.11	0.91	0.80

df: degree of freedom; RMSEA: Root mean square error of approximation; CFI: comparative fit index; NNFI: non-normed fit index

#In pre-determined model, the factor structure is pre-determined (#1, #2 and #3 with acute exacerbation management, #4, #5 and #6 with trigger avoidance, and #7, #8 with physical activity). The alternative model is derived from exploratory factor analysis, where #5 was loaded to physical activity)

To compare to the results in exploratory analysis, the correlation matrix of latent factors and the standardised regression weights of latent factors on their indicators of the three-factor predetermined model (figure 4-1) are shown in table 4-9 and table 4-

10. Three latent factors were moderately correlated (correlation coefficients between 0.57 and 0.69), and the standard regression weights were all >0.4.

TABLE 4-9 Correlation matrix of three latent factors in asthma-specific peer support

factor	1	2	3
1 acute exacerbation management	1		
2 trigger avoidance	0.69	1	
3 physical activity	0.57	0.66	1

TABLE 4-10 Regression weights of three latent factors on 8 observed items in asthma-specific peer support (3 factor structure)

factor	Standardised regression weights		
	1	2	3
1.Using inhaler when asthma attacks	0.76		
2.Telling adults when not feeling well	0.62		
3.Keeping inhaler at hand	0.76		
4.Taking care of self on cold days		0.82	
5.Staying away from pollution/smoke		0.69	
6.... away from those who have a cold		0.46	
7.Taking part in physical activity			0.67
8.Warming up and down thoroughly			0.69

Factor 1: acute exacerbation management; Factor 2: trigger avoidance; Factor 3: physical activity  
 $\chi^2=12.35$  (df=17, p=0.779), RMSEA<0.01, CFI=1.000, NNFI=1.195

### Summary

In this section, the psychometric properties of (adolescent reported) asthma-specific peer support and (parent reported) parent support scales were investigated. Despite some inconsistencies in the results, exploratory and confirmatory factor analysis generally indicated that the factor structure underlying the two support scales was consistent with the predetermined 3-factor structure (acute exacerbation management, trigger avoidance and physical activity) in the questionnaire developing process, which was also consistent with the factor structure underlying the adherence scales (shown in chapter 3). The consistencies in the factor structure across different scales reported by parents, adolescents and the combination of two further supported the internal validity of the adherence scale. In the main analyses of this chapter

(presented in section 4.4), the asthma-specific peer support scale and the asthma-specific parent support scale was calculated by adding 8 items in each scale (i.e. unweighted sum of 8 items). The Cronbach's alpha of asthma-specific peer support was 0.81, and the Cronbach's alpha of asthma-specific parent support was 0.72.

### **Peer social competence: peer acceptance**

As discussed in chapter 2, peer acceptance is an evaluative indicator of peer social competence, while peer stress-related coping activities are a behavioural indicator of peer social competence. Adolescents' peer acceptance scales, both self-report and parent-report, were derived from Harter's Child Social Competence Scale (Harter, 1982). The scales were based on respondents' agreement on seven descriptions about the adolescent: (1) The adolescent has a lot of friends. (2) The adolescent is popular with children. (3) The adolescent is likable. (4) The adolescent does things with children. (5) The adolescent finds it easy to make friends. (6) The adolescent is important to classmates. (7) Most adolescents like the adolescent. Instead of the original four-point interviewing scale for younger children, a five-point Likert self-administration scale was used for young adolescents and their parents.

All 86 parents and all 86 adolescents completed the peer acceptance questionnaires. The internal consistency (Cronbach's alpha) of adolescent-reported peer acceptance (7 items) and the internal consistency of parent-reported peer acceptance (7 items) were both 0.92. The descriptive analysis of adolescent-reported and parent-reported peer acceptance was shown in table 4-11. The distributions of adolescent-reported peer acceptance and parent-reported peer acceptance were both skewed to the right, which means most adolescents were reported as having good peer acceptance. Both adolescent- and parent- reported questionnaires had one low outlier (adolescent report = 7, parent-report = 16). They belonged to the same parent-adolescent dyad, and they were not excluded from the further analysis. The Spearman

correlation coefficient between adolescent-reported and parent-reported peer acceptance was 0.68 ( $p < 0.001$ ), indicating a moderate correlation between self-reported and parent-reported peer acceptance. In the main results of this chapter (section 4.4), although parent-reported peer acceptance was used as the primary indicator of peer acceptance, the benefit of including adolescent-reported peer acceptance in explaining asthma adherence was also investigated.

TABLE 4-11 Descriptive analysis of adolescent-reported and parent-reported peer acceptance

	N	Range	Median	25 <sup>th</sup> -75 <sup>th</sup> percentile	10 <sup>th</sup> -90 <sup>th</sup> percentile
Adolescent -reported	86	7-35	31	25-34	22-35
parent-reported	86	16-35	34	30-35	26-35

### **Peer social competence: coping activities**

The coping activity scale was adapted from the Kidcope questionnaire (younger children version), a 15-item questionnaire which has been used in children aged as young as 7 year-old and with chronic illnesses, including children in England (Spirito et al., 1991; Pretzlik, 1997). Adolescents were asked to recall and write down a recent bad experience with their friends, and choose one of the emotions they felt in the specified situation (nervous/anxious, sad/unhappy, and cross/angry). Then they were asked what they did in their situations among 15 coping activities on a three point scale (quite a lot, more or less, none). The 15 coping behaviours belonged to 10 coping strategies, according to previous studies (Pretzlik, 1997; Spirito and Stark, 1991) (table 4-12). The last question asked children to evaluate their satisfaction concerning what they had done with the situation on a five point scale (very good, good, okay, bad, very bad). There was no parent version of coping activity as the scale is used only for adolescents.

TABLE 4-12 Items of the coping strategy questionnaire

<b>Coping strategy</b>	<b>Item</b>
Distraction	1 Try to forget it
	2 Do something like watch TV or play to forget it
Social withdrawal	3 Stay on my own
	4 Keep quiet about the problem
Cognitive restructuring	5 Try to see the good side of things
Self-criticism	6 Blame myself for causing the problem
Blaming others	7 Blame someone else for causing the problem
Problem solving	8 Try to sort out the problems by thinking of answers
	9 Try to sort it out by doing something or talking to someone about it
Emotional regulation	10 Shout, scream, or get angry
	11 Try to calm myself down
Wishful thinking	12 Wish the problem had never happened
	13 Wish I could make things different
Social support	14 Try to feel better by spending time with others like family or friends
Resignation	15 Do nothing because the problem won't be sorted anyway

The questionnaire was simplified from the original design because it only asked for one social experience -- there were 4 social experiences in the original design, but pilot tests revealed this questionnaire took much more time than expected.

Meanwhile, the original questionnaires was binary items (yes and no), while a 3-point ordinary items were used in this questionnaire (quite a lot, more or less, none). It was unfair to judge their social competence based on their coping activities on just a single occasion. However, as young adolescents had limited patience answering questions, the questionnaire space was precious and it was impossible to include more items in this research. In the study, it was found that many adolescents reported that they could not recall any bad experiences, and failed to complete this part of questionnaire. In fact, only 71 of 86 adolescents (83%) completed the coping style questionnaire.

Among the other 15 adolescents, 1 adolescent only answered 8 items (15 items in total), 8 adolescents reported that they did not have bad experiences with friends, and 6 adolescents skipped this part of questionnaire.

TABLE 4-13 Descriptive analysis of items in coping style questionnaires (child-reported)

Item	Mean±SD	Memo*
1 Try to forget it	2.1±0.6	
2 Do something like watch TV or play to forget it	1.9±0.9	
3 Stay on my own	1.4±0.7	Low
4 Keep quiet about the problem	2.0±0.8	
5 Try to see the good side of things	2.2±0.8	High
6 Blame myself for causing the problem	1.4±0.6	Low
7 Blame someone else for causing the problem	1.9±0.9	
8 Try to sort out the problems by thinking of answers	1.9±0.7	
9 Try to sort it out by doing something or talking to someone about it	2.0±0.8	
10 Shout, scream, or get angry	1.5±0.7	Low
11 Try to calm myself down	1.9±0.8	
12 Wish the problem had never happened	2.5±0.7	High
13 Wish I could make things different	2.3±0.8	High
14 Try to feel better by spending time with others like family or friends	2.2±0.8	High
15 Do nothing because the problem won't be sorted anyway	1.5±0.7	Low

\*high/low indicates a relative high/low frequency among 15 items

Table 4-13 showed the descriptive analysis of 15 items in the coping style questionnaire. The means of items fell between 1.4 and 2.5 (1=not at all; 2=more or less; 3=yes). The most used strategies (mean>2.2) was #5 (trying to see the good side of things), #12 (wishing the problem had never happened), #13 (wishing I could make things different), and #14 (trying to feel better by spending time with others like family or friends). The least used strategies (mean<1.6) was #3 (staying on my own), #6 (blaming myself for causing the problem), #10 (shouting, screaming, or getting angry), and #15 (doing nothing because the problem won't be sorted anyway). Simply to conclude from these mean values, it seems that positive thinking strategies are more frequently used than negative thinking strategies.

The Kendall's tau inter-item correlation matrix is shown in table 4-14. Because the predetermined factor structure was only indicative (not statistically validated) in the literature, a consistent pattern was not seen through visual comparison. There were no particular correlative patterns among the high-frequency items and low-frequency items, either. The internal consistency (Cronbach's alpha) of all 15 items was 0.469.

TABLE 4-14 Inter-item correlation matrix of coping style scale (Kendall's tau)

	#01	#02	#03	#04	#05	#06	#07	#08	#09	#10	#11	#12	#13	#14
#01	1.00													
#02	0.25*	1.00												
#03	-0.03	-0.06	1.00											
#04	0.15	-0.04	0.08	1.00										
#05	0.31*	0.31*	-0.15	0.10	1.00									
#06	-0.10	-0.01	0.32*	0.22*	-0.05	1.00								
#07	0.02	-0.26*	-0.04	-0.05	-0.33*	-0.13	1.00							
#08	0.27*	0.11	0.09	-0.08	0.16	0.09	0.03	1.00						
#09	-0.10	-0.08	-0.05	-0.29*	-0.20	-0.09	0.12	0.18	1.00					
#10	-0.11	-0.33*	0.23*	-0.13	-0.28*	0.19	0.31*	-0.05	0.12	1.00				
#11	0.08	0.21	0.14	-0.01	0.17	0.08	0.01	0.10	-0.02	-0.01	1.00			
#12	0.01	-0.02	0.21	-0.09	0.00	0.19	0.06	0.20	0.10	0.14	0.14	1.00		
#13	0.11	-0.13	0.12	0.25*	0.06	0.29*	0.09	0.26*	0.08	0.11	0.23*	0.31*	1.00	
#14	0.17	0.12	0.08	-0.05	0.16	-0.08	-0.11	0.17	0.26*	-0.03	0.12	0.14	0.01	1.00
#15	0.04	0.05	0.38*	-0.06	-0.01	0.22	0.13	0.01	-0.06	0.26*	-0.01	0.22*	0.13	0.15

TABLE 4-15 Exploratory factor analysis, coping style scale

	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
#01	.052	.004	.008	.831	-.165
#02	.683	.017	-.187	.303	.042
#03	.095	.767	.178	-.110	-.088
#04	-.015	-.092	.268	.137	-.725
#05	.508	-.177	.053	.489	-.168
#06	.188	.323	.548	-.315	-.270
#07	-.766	.128	-.087	.243	.060
#08	.078	-.045	.362	.518	.275
#09	-.181	-.150	.178	-.062	.790
#10	-.484	.563	.166	-.150	.094
#11	.390	.107	.303	.170	.093
#12	.044	.260	.638	.044	.215
#13	-.149	-.040	.833	.188	-.149
#14	.234	.102	.115	.351	.462
#15	-.129	.821	.008	.122	.048

Extraction Method: Principal Component Analysis. Rotation: Varimax with Kaiser Normalization.

Exploratory factor analysis (table 4-15) was not successful although Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.536, and the significance of Bartlett's test of sphericity was <0.001, indicated the correlation matrix was not "identical." Using principle component and varimax rotation methods, 5 factors with eigenvalue>1 were extracted. However, a typical simple structure was not seen in the correlations between factors and items (i.e. many cross-loading items), and the results

did not improve substantially when the factor numbers were restricted to 4, 3 or 2.

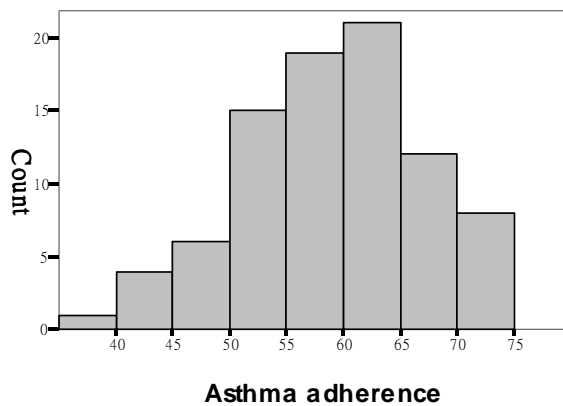
To summarise, although the questionnaires were designed to cover a range of coping activities, there was no evidence to support a clear underlying factor structure, but at the mean time a single factor structure was not supported by internal consistency (0.469). This unsatisfactory psychometric property may be due to the methodological differences – compared to this questionnaire, a standard Kidcope questionnaire asked respondents to recall 4 different unspecific scenarios and rate on 2-point scales, while in the modified questionnaire of this study, respondents were asked to recall only 1 scenario specifically in peer problems and rate on 3-point scales. Another possibility is related to the heterogeneity in this questionnaire (10 factors in 15 items). In fact, internal consistencies and underlying factor structures of Kidcope have never been demonstrated in previous studies (Edgar and Skinner, 2003; Pretzlik, 1997). Therefore, further studies are still required to improve this questionnaire among young populations. Meanwhile, study 4 of the thesis (chapter 6) has investigated adolescents' coping behaviour qualitatively, and the results between the two studies are compared and discussed in chapter 7 (discussion and conclusion). Due to the poor internal consistency, it was decided that the Kidcope coping activity scale was not included into the final analysis of this study, leaving peer acceptance the only indicator of social competence in this study. Therefore, the final social environmental factors included in the main analysis (section 4.4) were asthma-specific parent support, asthma-specific peer support, parent-reported peer acceptance and adolescent-reported (or self-reported) peer acceptance.

#### **4.4 Results**

To refresh the memory after extensive discussion of social environmental measures -- the purpose of the study is a) to explain asthma adherence with social environmental variables (asthma-specific parents support, asthma-specific peer

support, and peer acceptance) and b) to explain the age-related decline in asthma adherence with social environmental variables. Adherence was viewed as a uni-dimensional construct covering three different dimensions of asthma management (acute exacerbation management, trigger avoidance and physical activity) and also covering perspectives from two types of informants (adolescents and parents). The internal consistency of the adherence scale was 0.78. Among the 86 dyads, the range of adherence was between 36 and 75, and the mean and standard deviation were 59.5 and 8.2. Figure 4-2 shows a histogram of parent-child combined adherence. The Shapiro-Wilk test suggested that the distribution was not significantly different from the normal distribution ( $p=0.38$ ).

Figure 4-2 Histogram, distribution of parent-adolescent combined adherence scale



### **Bivariate associations with asthma adherence**

Firstly, bivariate analyses between asthma adherence and social environmental variables were conducted. Normality of the distributions of social environmental variables was tested with the Shapiro-Wilk normality test. As a result, except for the distribution of asthma-specific peer support scale, the distributions of all other scales (parent-reported peer acceptance, adolescent-reported peer acceptance and asthma-specific parent support) were significantly different from the normal distribution

( $p < 0.05$ ). Therefore, Spearman correlation ( $\rho$ ) was used to investigate the bivariate relationships between adherence and psychological variables. The results are shown in table 4-16. In brief, higher asthma-specific peer support and higher asthma-specific parent support were significantly correlated with better asthma adherence to the level of  $p < 0.001$  ( $\rho = 0.53$  and  $0.63$ , respectively). Higher adolescent- and parent- reported peer acceptance scales were also correlated with better asthma adherence, but only at borderline significance levels.

TABLE 4-16 Bivariate analysis, psychological variables and asthma adherence

	Spearman rho#	P value
Asthma-specific social environment		
Peer support	0.53*	<0.001
Parent support	0.63*	<0.001
Peer acceptance		
Adolescent-reported	0.21	0.053
Parent reported	0.26*	0.02

\* $p < 0.05$

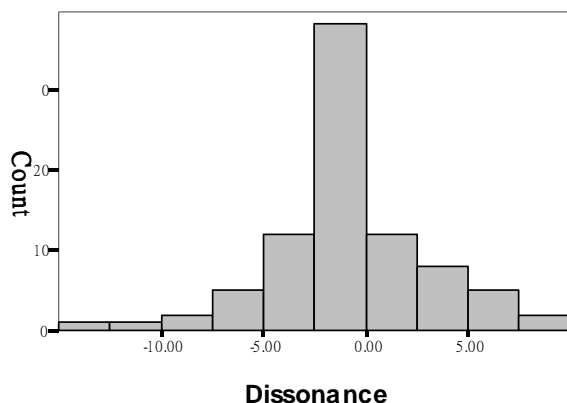
#Spearman rho correlation coefficient(s) with asthma adherence

### Bivariate associations with parent-adolescent dissonance

To evaluate how parents and young adolescents differ in the report of asthma adherence as a possible indicator of family relationships in the context of asthma management, a parent-adolescent dissonance score was calculated by subtracting the standardised parent-reported adherence scale (the sum of eight parent-reported items) with the standardised adolescent-reported adherence scale (the sum of eight adolescent-reported items). Therefore, a higher score indicates the tendency of parents to estimate higher adherence than their adolescents. The range of parent-adolescent dissonance was between  $-0.76$  and  $0.65$ . The mean and standard deviation are  $-0.001$  and  $0.028$ . The  $p$  value of Kolmogorov-Smirnov test of normality was  $0.006$ , suggesting the distribution was significantly different from normal distribution. The skewness was  $-0.13 \pm 0.26$ , and kurtosis was  $1.01 \pm 0.51$ . Therefore, a typical normal

distribution is flatter. The histogram is shown in figure 4-3.

Figure 4-3 Histogram, parent-adolescent dissonance score



Pearson correlation coefficients between parent-adolescent dissonance and major variables in this study are presented in table 4-17. In this sample, parent-adolescent dissonance was not correlated with the combined adherence score ( $r=0.06$ ,  $p=0.61$ ). Parents tended to estimate adherence significantly higher than adolescents when the age was older ( $r=0.22$ ,  $p=0.047$ ) and when parents reported higher support of asthma management ( $r=0.29$ ,  $p=0.01$ ). However, these correlations were controversial because they were attenuated when the correlation was calculated with Spearman rho. The Spearman rho was 0.21 ( $p=0.054$ ) with age, and 0.19 ( $p=0.09$ ) with parent support, both failing to reach accepted level of significance. Therefore, there is no clear evidence in this study showing any significant social environmental factor associated with parent-adolescent dissonance of asthma adherence. More importantly, there was no association between parent-adolescent dissonance and asthma adherence ( $r=0.06$ ). Therefore, it was decided not to be included in the multivariate analysis that explained adherence behaviour in the next section.

TABLE 4-17 Bivariate correlation, parent-child dissonance and other variables

	Correlation coeff	P value
Age	0.22	0.047*
Medication level	0.09	0.42
Father's highest educational qualification	-0.21	0.05
Mother's highest educational qualification	-0.02	0.86
Parent support of asthma management	0.29	0.01*
Peer support of asthma management	-0.13	0.22
Parent-reported social competence	0.06	0.56
Self-reported social competence	-0.10	0.35
Combined adherence score	0.06	0.61

### Explaining (or predicting) adherence

Hierarchical models were used to predict asthma adherence using multiple linear regression. These appear in table 4-18. Sociodemographic variables (age, gender, father and mother's educational qualification) were entered initially, followed by medication level, asthma-specific social support (peer and parent support), and peer acceptance (adolescent report and parent report)). As shown in the table, socio-demographic status explained 13% of the variance in asthma adherence (model 1), and the model was significantly different from the null hypothesis. This shows that sociodemographic status predicts asthma adherence, with p value at 0.02. Adding medication level into model 1 explained additional 8% of variance in asthma adherence ( $R^2=0.21$ ,  $p=0.002$ ), and the model was significantly better than model 1 ( $p=0.007$ ) in explaining asthma adherence. In model 3, asthma-specific social support (peer support and parent support) was added into model 2. Adding asthma-specific social support substantially explained 30% of variance in addition to model 2 ( $R^2=0.51$ ,  $p<0.001$ ), and the model was significantly better than model 2 ( $p<0.001$ ). In model 4, peer acceptance (adolescent-reported and parent-reported peer acceptance) was added in model 3. The additional variables explained 5% variance in addition to model 3 ( $R^2=0.56$ ,  $p<0.001$ ), and the model was significantly better than model 3 ( $p=0.03$ ).

TABLE 4-18 Hierarchical predicting models of asthma adherence

Block	Variables
Block 1	Sociodemographic (age, gender, father qualification, mother qualification)
Block 2	Medication level
Block 3	Asthma-specific social support (peer support, parent support)
Block 4	Peer acceptance (adolescent-reported and parent-reported)

Model	R <sup>2</sup>	P value	P value (F change)
#1 Block 1	0.13	0.02	0.02
#2 Block 1+2	0.21	0.002	0.007
#3 Block 1+2+3	0.51	<0.001	<0.001
#4 Block 1+2+3+4	0.56	<0.001	0.03

TABLE 4-19 Standardised regression coefficients and p values in predicting models

Variables	Standardised regression coefficient (beta)			
	Model 1	Model 2	Model 3	Model 4
<b>Sociodemographic variables</b>				
Age	-0.32*	-0.29*	-0.17	-0.13
Gender (boys=1, girls=2)	0.05	0.05	0.08	0.06
Father qualification	0.04	0.001	0.01	-0.03
Mother qualification	-0.18	-0.12	0.14	0.17
<b>Asthma status</b>				
Medication level		0.28*	0.16	0.21*
<b>Asthma-specific social support</b>				
Asthma specific peer support			0.26*	0.26*
Asthma-specific parent support			0.48*	0.45*
<b>Peer acceptance</b>				
Child-reported peer acceptance (Excluded)#				--
Parent-reported peer acceptance				0.22*

# adolescent-reported peer acceptance was excluded due to high collinearity with parent-reported peer acceptance ( $r=0.7$ )

\*  $p<0.05$

The standardised regression coefficients and p values of model 1, 2, 3 and 4 are shown in table 4-19. Adolescent-reported social competence was excluded due to high collinearity with parent-reported social competence ( $r = 0.7$ ). As shown in the table, asthma-specific peer support, asthma-specific parent support and parent-reported peer acceptance were significant independent predictors of asthma adherence. Among socio-demographic variables, age was the only independent variable initially, but the effect was attenuated and became non-significant when the effect of asthma-specific

social support was controlled for. The effect of medication level was also attenuated when the effect of asthma-specific social support was controlled for, but the effect was restored when peer acceptance was added into the model.

*Peer acceptance-related interaction effects*

Attempts were made to investigate the interaction between parent-reported peer acceptance and asthma-specific peer support or parent support (table 4-20). To avoid multi-collinearity in estimating the coefficients, the interaction terms were the residuals of multiplicative terms regressed on the contributory terms. For example, the interaction term between parent-reported peer acceptance and asthma-specific peer support were the residuals obtained from the regression model where the multiplicative term were predicted by parent-reported peer acceptance and asthma-specific peer support (Spratt et al., 2005; Burrill, 1997).

An additional block of variables, consisting of two interaction terms, were added to the hierarchical linear regression model (table 4-20). The two interaction terms significantly explained 4% of variance in asthma adherence in addition to model #4.

TABLE 4-20 Extended hierarchical predicting models (adding social competence interactions)

Block	Variables
Block 1	Sociodemographic (age, gender, father qualification, mother qualification)
Block 2	Medication level
Block 3	Asthma-specific social support (peer support, parent support)
Block 4	Peer acceptance (adolescent-reported and parent-reported)
Block 5	Parent-reported peer acceptance * peer support Parent-reported peer acceptance * parent support

Model	R <sup>2</sup>	P value	P value (F change)
#1 Block 1	0.13	0.02	0.02
#2 Block 1+2	0.21	0.002	0.007
#3 Block 1+2+3	0.51	<0.001	<0.001
#4 Block 1+2+3+4	0.56	<0.001	0.03
#5 Block 1+2+3+4+5	0.59	<0.001	0.04

TABLE 4-21 Regression coefficients of the extended hierarchical predicting models (adding social competence interactions)

Variables	Model 4 Standardised regression coefficient (beta)	P value	Model 5 Standardised regression coefficient (beta)	P value
<b>Sociodemographic variables</b>				
Age	-0.13	0.12	-0.16	0.051
Gender (boys=1, girls=2)	0.06	0.47	-0.01	0.95
Father qualification	-0.03	0.77	-0.08	0.38
Mother qualification	0.17	0.08	0.16	0.09
<b>Asthma status</b>				
Medication level	0.21*	0.01	0.25*	0.004
<b>Asthma-specific social support</b>				
Asthma-specific peer support	0.26*	0.004	0.30*	0.002
Asthma-specific parent support	0.45*	<0.001	0.43*	<0.001
<b>Peer acceptance</b>				
Adolescent-reported peer acceptance	--		--	
Parent-reported peer acceptance	0.22*	0.007	0.24*	0.03
<b>Interaction</b>				
Asthma-specific peer support *			-0.23*	0.008
Parent-reported peer acceptance *				
Asthma-specific parent support *			0.16	0.05
Parent-reported peer acceptance				

The regression coefficients are shown in table 4-21. The regression coefficients and the significance levels of the non-interactive terms were not substantially changed after the interaction terms were introduced. Between the two interaction terms, the interaction between asthma-specific peer support and parent-reported peer acceptance was significant ( $p=0.008$ ), while the other interaction term (parent support \* peer acceptance) was not. The results indicate that the positive effect of peer acceptance on asthma adherence is attenuated when peer support is high, or that the positive effect of peer support on asthma adherence is attenuated when young adolescents feel accepted by peers.

### *A brief discussion of current results*

To summarise the results presented so far in this cross-sectional sample of 9-14 year olds, both the asthma-specific social support (measured as asthma-specific parent support and peer support) and peer acceptance predicted asthma adherence independent of background variables, including age, gender, parental educational qualification and medication level. Meanwhile, compared to the model with socio-demographic factors, medication level and asthma-specific social support, adding adolescent's peer acceptance significantly explained an additional 5% of variance in asthma adherence. When the effect of social environmental factors (specific social support and peer acceptance) was taken into account, there was no significant effect of socio-demographic variables (age, gender and parental education) on asthma adherence, but there was a significant effect of medication level on asthma adherence. Finally, a significant negative interaction was found between the effect of peer support and the effect of peer acceptance on asthma adherence.

As discussed in chapter 2, the significant effect of the social environment on actual behaviour is well known in health psychology (de Bruijn et al., 2007; Armitage, 2005). Social environment interacts with knowledge and attitude, and reinforces young adolescents' willingness to manage their asthma. Alternatively, the social environment may occupy adolescents' thinking process, and promote selective information to be included in adolescents' decision making process (Harakeh et al., 2004; Honda and Kagawa-Singer, 2006; Motl et al., 2007). It was not the intention of the study to investigate the mechanism of each pathway. Whichever mechanism dominates, the study demonstrated the important role of young adolescents' social environment in adherence to asthma management behaviour.

Although the effect of social support on asthma management has been shown in previous studies of chronic asthma medication in similar or younger populations (van

Dellen et al., 2008; Chen et al., 2007a; Cohen et al., 2003), a novel result in this study was to demonstrate the strong effect of both asthma-specific parental support and peer support on a *summative* assessment of asthma adherence in acute exacerbation management, trigger avoidance and physical activity. Meanwhile, a strong influence of parental support on asthma adherence was found in this study (beta = 0.45), despite the popular belief, often in the media, that children do not listen to their parents during adolescence. Nonetheless, asthma-specific peer support did have a significant effect on asthma adherence in the study sample. The standardised regression coefficient beta was 0.25, smaller than that of asthma-specific parental support. However, the sizes of standardised coefficient are sensitive to the reliability of a measure, and therefore conclusions regarding the relative influence between parent and peer support should be made cautiously.

Asthma-specific peer support and asthma-specific parent support were peers' or parents' specific social support for asthma management behaviour. By contrast, peer acceptance was used as an indicator of social competence among peers in this study, which is a non-specific aspect of the peer environment (see chapter 2). The role of social competence in relation to the peer environment has been demonstrated in adolescents' drinking behaviour (Epstein et al., 2007). In a large scale longitudinal survey of 1318 adolescents, higher rates of peer drinking and lower social skills predicted adolescents' current drinking behaviour and 3-year future drinking behaviour. Meanwhile, there was an interaction effect on adolescents drinking behaviour between peer drinking and adolescents' refusal skills -- better refusal skills were associated with smaller positive effects of peer drinking on adolescent drinking behaviour. Similarly, in the current study, young adolescents' social competence predicted asthma adherence independent of the effect of asthma-specific peer support and asthma-specific parent support, and there was a significant negative interaction between asthma-specific peer support and social competence. In other words, the negative effect of poor support in the social environment could be compensated by the

positive effect of high social competence, and the benefit of social competence is particularly prominent in adverse peer environment (but not adverse parent environment). The independent effect and the negative interaction both indicate that social competence is a resilience factor in asthma-unfriendly environments.

However, social competence is more than peer acceptance. In the current study, unfortunately, the scale of coping activities was not reliable among this group of participants, and thus was not included in the analysis. Therefore, we would not be able to examine the distinction between peer acceptance and social competence directly in explaining asthma adherence in early adolescence. However, by including peer acceptance and asthma-specific peer support simultaneously in this study, the “net” effect of peer acceptance independent of asthma-specific peer support may also be attributed to the non-contextual social skills.

#### *Self-reported and parent-reported peer acceptance*

In the previous results, the independent effect of self-reported peer acceptance was not shown due to multi-collinearity with parent-reported peer acceptance. However, it would be interesting to see how the effect of self-reported peer acceptance differed from parent-reported peer acceptance. Therefore, in the following regression models, the effect of adolescent-reported peer acceptance was investigated when parent-reported peer acceptance was excluded from the analysis in order to estimate this effect. In contrast to parent-reported peer acceptance which was not associated with asthma-specific social support, adolescent-reported peer acceptance was correlated with asthma-specific peer support and asthma-specific parent support (table 4-22). Despite the difference in significance levels, the correlation coefficient (Spearman rho) between asthma-specific parent support and adolescent-reported peer acceptance was similar to the correlation coefficient between asthma-specific parent

support and parent-reported peer acceptance (0.21 vs. 0.26), but the correlation coefficient between asthma-specific peer support and adolescent-reported peer acceptance was much larger than the correlation coefficient between asthma-specific peer support and parent-reported peer acceptance (0.28 vs. 0.10).

TABLE 4-22 Spearman correlation coefficients between psychological variables, parent-reported and adolescent-reported social competence scale

	Age	Asthma-specific peer support	Asthma-specific parent support	Parent-reported peer acceptance
Peer acceptance Parent-reported	-0.10	0.10	0.21	1
Adolescent-reported	-0.20	0.28*	0.26*	0.68*

\*p<0.05

TABLE 4-23 Standardised regression coefficients and p values in model 4, parent-reported peer acceptance replaced with adolescent-reported peer acceptance

Variables	Adolescent-reported		Parent-reported	
	Standardised regression coefficient (beta)	P value	Standardised regression coefficient (beta)	P value
<b>Sociodemographic variables</b>				
Age	-0.14	0.10	-0.13	0.12
Gender (boys=1, girls=2)	0.09	0.24	0.06	0.47
Father qualification	0.002	0.99	-0.03	0.77
Mother qualification	0.15	0.14	0.17	0.08
<b>Asthma status</b>				
Medication level	0.20*	0.02	0.21*	0.01
<b>Asthma-specific social support</b>				
Asthma-specific peer support	0.24*	0.01	0.26*	0.004
Asthma-specific parent support	0.45*	<0.001	0.45*	<0.001
<b>Peer acceptance</b>				
Adolescent-reported peer acceptance	0.14	0.10	--	
Parent-reported peer acceptance			0.22*	0.007

\* p<0.05

Adolescent-reported social competence was used to replace parent-reported peer acceptance in the regression model 4 to predict children asthma adherence after other

covariates were controlled for (age, gender, father and mother qualification, medication level, asthma-specific peer support and asthma-specific parent support). The results are compared with the original model (where parent-reported peer acceptance was used) in table 4-23. Unlike parent reports, adolescent-reported peer acceptance was not a significant predictor of asthma adherence independent of other covariates. Although adolescent-reported peer acceptance was correlated with asthma-specific peer support and asthma-specific parent support, inclusion of adolescent-reported peer acceptance did not intervene with the predictability (beta coefficient) of asthma-specific peer support and asthma-specific parent support between the two models.

As mentioned earlier, peer acceptance is the evaluation of social competence. It is therefore relevant *who* evaluated the peer acceptance, and peer acceptance reported by teachers, parents and children/adolescents tend to have inconsistent results (Hussong et al., 2005; DuBois and Silverthorn, 2004a). Although in this study the correlation between parent-reported peer acceptance and adolescent-reported peer acceptance was high, adolescent-reported peer acceptance is social self-concept, whilst parent-reported peer acceptance was an external evaluation of young adolescents' social competence. It is therefore not surprising to see that, compared to parent-reported peer acceptance, adolescent-reported peer acceptance had higher correlations with adolescent-reported asthma-specific peer support (because they are both self-reported). It may explain why it was the external evaluation of social competence that independently and significantly explained asthma adherence -- because the external evaluation is a more distinct construct than social self-concepts compared to self-reported asthma-specific peer support.

### **Explaining age effect**

The results of the study so far seem to support that specific social support and

social competence can not only explain asthma adherence in early adolescence, but also explain the age-related decline in asthma adherence. In this study, further analyses were performed to investigate the possible mechanisms in the relationship between age and adherence. As shown in table 4-24, an older age was correlated with lower asthma-specific peer support (Spearman rho=-0.27, p=0.01), but not correlated with medication level, asthma-specific parent support or parent-reported peer acceptance. Another finding in this correlation matrix is the positive correlation coefficients between medication level and asthma-specific social supports, in contrast to a negative correlation between medication level and parent-reported peer acceptance (although not all statistically significant). This can help to explain the inconsistency in the effect of medication level in the hierarchical models presented in the previous section.

TABLE 4-24 Spearman correlation between age, asthma-specific peer support, asthma-specific parent support and parent-reported peer acceptance

	Age	Medication level	Peer support	Parent support
Age	1			
Medication level	-0.11	1		
Peer support	-0.27*	0.16	1	
Parent support	-0.12	0.27*	0.48*	1
Parent-reported peer acceptance	-0.10	-0.11	0.10	0.21

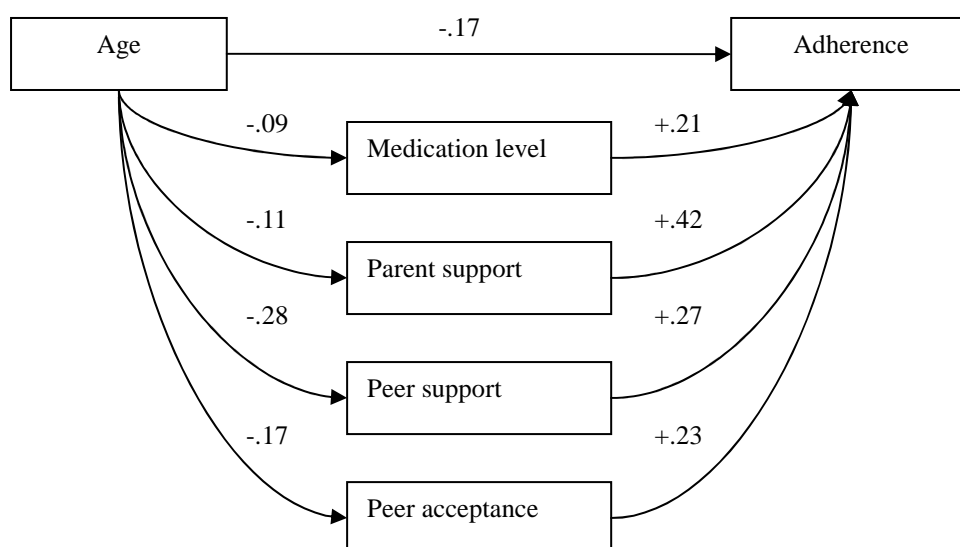
Table 4-25 showed partial correlation coefficients between age and adherence when the effect of each variable was controlled for. The correlation was substantially altered only when the effect of asthma-specific peer support was controlled for -- the negative correlation between age and adherence was attenuated, and the partial correlation coefficient became non-significant when the effect of asthma-specific parent support was controlled for. By contrast, the correlation coefficients were not altered when the effect of medication level, asthma-specific parent support or parent-reported peer acceptance was controlled for. These results suggest that among the social environmental variables, asthma-specific peer support is accounted for the age-related decline in early adolescence. In other words, older adolescents have poorer

asthma adherence because they perceive lower asthma-specific peer support when they are older.

TABLE 4-25 (Pearson) partial correlation between age and adherence when the effect of social environmental factors are controlled for

Controlled for	Partial correlation	P value
--	-0.32	0.003
Medication level	-0.31	0.004
Asthma-specific peer support	<b>-0.21</b>	0.05
Asthma-specific parent support	-0.32	0.003
Parent-reported peer acceptance	-0.29	0.008

Figure 4-4 Path analysis, mediation analysis of age effect on asthma adherence



Path	Association through the path	(%)
Direct path	-0.17	49%
Indirect path	-0.18	51%
Medication level	-0.02	6%
Asthma-specific peer support	-0.04	11%
Asthma-specific parent support	-0.08	23%
Parent-reported peer acceptance	-0.04	11%
Total effect	-0.35	100%

Path analysis was used to investigate the possible mediating effect of social environmental variables in the relationship between age and asthma adherence. This method is similar to partial correlations, but the weight of each mediating pathways

can be estimated. The sample size was more than 10 times of the number of variables, which is therefore acceptable for significance test in path analysis (Kline, 1998). However, only the correlation coefficients (not significant level) are discussed here, and thus sample size is generally not an issue. As shown in figure 4-4, a mediation pathway through peer support explained 23% of the total effect of age on asthma adherence, followed by the pathways through parent support and peer acceptance, both explained 11% of the age effect. In total, the social environmental variables (parent support, peer support and peer acceptance) explained 45% of the total age effect on asthma adherence.

Using mixed linear model, attempts were made to introduce into model 4 (table 4-21) a term of interaction between age and asthma-specific peer support, between age and asthma-specific parent support, or between age and parent-reported social competence. None of the above three interaction terms had significant fixed effect on the combined adherence.

#### *Discussion of the age-related adherence decline in early adolescence*

Although many previous studies emphasise poor asthma adherence in adolescence, the relationship between age and asthma adherence has been under-investigated using quantitative methods (McQuaid et al., 2003; Logan et al., 2003). In our 9-14 year old sample, an older age was associated with poorer asthma adherence. However, age did not predict asthma adherence when the effect of the social environmental variables were controlled for. Meanwhile, there was a significant correlation between an older age and poorer asthma-specific peer support, and partial correlation analysis showed that the significant correlation between age and adherence was attenuated when the effect of asthma-specific peer support was controlled for. In other words, whilst asthma-specific parent support remains at the same level as children grow older, asthma-specific peer support gradually declines with age, which

explained the poorer asthma adherence at an older age. Although parents have been shown in the regression analysis to have a greater impact than peers on asthma adherence, it was the change in the peer environment that explained the decline of asthma adherence at older age rather than the contribution of parental support.

However, it should be clarified that the asthma-specific peer support in this study was measured by self report. To be precise, the correlation between age and adherence was explained by *perceived asthma-specific peer support*, which might not always be the “actual” peer support. Another relevant question is whether young adolescents were becoming more sensitive to peer influence or becoming less sensitive to parent influence. There was no age-peer or age-parent interaction found in this study. However, the statistical power in the analysis was not strong enough to support or deny the existence of age-related interaction effects on asthma adherence in early adolescence. Therefore, this evidence is suggestive but not conclusive.

#### **4.5 Summary and Conclusion**

In this associative (cross-sectional) study, the family and peer social environment of early adolescence were investigated to explore who was responsible for the age-related decline in asthma adherence. Firstly, the asthma-specific parent and peer support significantly explained asthma adherence, and it seems that asthma-specific parent support is a stronger predictor than asthma-specific peer support in early adolescence. Secondly, some aspects of peer social competence were investigated in this study. Unfortunately, the coping activity scale did not prove to be a reliable measure for participants, and therefore peer acceptance remained the only indicator of social competence. As a result, parent-reported peer acceptance was an independent predictor of asthma adherence, and the predicting effect was stronger when adolescents perceived a lower level of asthma-specific peer support. Therefore, the study supports the fact that social competence was indeed a *resilience factor* in

asthma adherence, as it is a resilience factor for other adolescent outcomes, such as school achievement and behavioural problems (Niles et al., 2008; Luthar et al., 2000; Niles et al., 2006; Gardner et al., 2008). Finally, partial correlations and path analysis were used to explain the age-related adherence decline with social environmental variables. Among the social environmental factors (asthma-specific parent/peer support and peer acceptance), although asthma-specific parent support was the strongest predictor of asthma adherence, it was the lower level of asthma-specific peer support perceived by adolescents that explained the age-related decline of asthma adherence.

#### *Validity and relevance of the study*

A small-scale, non-representative sample was used in the study. The limitation of this sample has been discussed in chapter 3. Meanwhile, this is a cross-sectional study. Although key background factors were controlled for, it was not possible to include all conceivable variables in the study. The possibility of spurious correlation and reverse causality cannot be excluded, and the statistical predictions require prospective studies to confirm. Nevertheless, the current study provides useful information for designing an intervention, which may in turn confirm the statistical predictions and lead to stronger, more causal claims.

The study was not able to adopt a comprehensive, hierarchical theoretical framework that includes all relevant predictors of asthma adherence. However, it was not the purpose of the study to *model* asthma adherence, but to investigate the relationships between asthma adherence and the social environment in early adolescence. Nevertheless, there are certain omitted variables in the study that might hamper internal validity. Firstly, items related to adherence to controller medications did not apply to every child in this sample, and were not included into the analysis. Secondly, the study did not include many knowledge and attitudinal factors (e.g. self-

efficacy) which are frequently considered in behavioural psychology. Thirdly, the variables in this study were respondent-dependent (i.e. adolescent reported or parent reported), and information of variables was not obtained from all respondents. Therefore, generalising the results to other omitted causal pathways should also be avoided. Finally, there are still many other aspects of the social environment remaining un-investigated in this study, such as adolescents' relationships with parents or with teachers, and many of them were explored qualitatively in study 3 and 4 (chapter 5 and 6) to increase our knowledge and understanding of the social environment in the context of young adolescents' asthma management.

Nevertheless, this study demonstrated the relationship between older age and poorer asthma adherence in early adolescence (age 9-14), and explained asthma adherence through the contribution of social environmental factors. With recognition of research limitations, the study provides quantitative evidence to support the role of social competence as a resilience factor in face of an adverse peer environment related to asthma management. This result may provide useful information for school or medical interventions where asthma care is considered.

## **Chapter 5**

### **The social environment of asthma management: the perspectives of adults (study 3)**



## 5.1 Introduction

In contrast to the previous two chapters where quantitative results were presented to demonstrate the association between asthma adherence and the social environment, a qualitative approach is adopted in the studies of this chapter and the next chapter. As discussed in chapter 2, there are direct influences of the social environment on our behaviour from other people (e.g. specific social support), and also indirect influences via our relationships with others, sometimes referred to as social capital. Peer acceptance, for example, represents one aspect of social relationships that influence adolescent behaviour. In this study, adults' views on young adolescents' social relationships were investigated, and the direct or indirect influence of the social environment on asthma management behaviour was explored qualitatively. This includes the views of parents and school staff on adult-adolescent relationships and peer relationships. Although there have been studies in educational and developmental psychology that identify the characteristics of a supportive adult-adolescent relationship in a family and among peers, whether or how these characteristics apply to a supportive teacher-adolescent relationship is relatively under-investigated. More importantly, whether or how these characteristics are supportive in chronic illness management is still largely unknown in the literature. The responsibility for disease care, for example, is a unique topic in adolescent chronic illnesses that is worth further exploration beyond our current knowledge in developmental psychology.

Therefore, the purpose of this study is to explore the characteristics of the behaviour or activities of others or the relationships with others (e.g. adult-related social environment) in the context of asthma management in early adolescence, through semi-structured interviews with a sample from two of the most important adult perspectives, parents and school staff. Firstly, the study explored how asthma management behaviour was *known and understood* by parents and school staff. Next,

the social environment with adults and with peers is presented separately. In investigating the social environment with adults, the behaviour or activities of adults and characteristics of adult-adolescent relationships that may support or hinder asthma management in early adolescence were explored, and the perspective of parents and the perspective of school staff were compared. In investigating the social environment with peers, likewise, the behaviour and activities in adolescents' peer relationships (understood by parents and school staff) that may support or hinder asthma management in early adolescence were explored. Having been aware of the literature on the characteristics that describe social relationships in adolescence, the information in this study is expected to improve our contextualised knowledge by describing whether or how these characteristics apply to the social environment of young adolescents with asthma.

One important question is whether or not this study focuses on adults' *perception* of the social environment of early adolescence. By asking this question, one should also be aware of the epistemological discussion in chapter 2 concerning whether or not knowledge can be approached without investigating human values. With a pragmatic epistemological approach, this study tried not to be committed to any epistemological claim. Therefore, although the research question was approached in this study through investigating some perceptions of interviewees around this topic, using the term "perceived social environment" is avoided as it may over-simplify the purpose of this study by assuming an objective, or "actual" social environment.

## **5.2 Participants and Methods**

### *Participants*

The participants of the study included school staff members and parents of adolescents with asthma recruited from the same schools and medical general

practices described earlier (chapter 3). They were invited to join a face-to-face interview for half hour to talk about their views on young adolescents' asthma management. Those who had been invited but thought they were not the best person to be interviewed were asked to name a suitable school staff member in the school or a suitable caretaker at home. The interview was one-to-one in principle, but the interviewees were encouraged to invite other appropriate interviewees to join. In total, there were 33 school staff interviews and 36 parent interviews. The profiles of participants and interviews are summarised in table 5-1<sup>8</sup>. The study was approved by the local ethics committee. A summary of ethical considerations is presented in the appendix.

#### *School staff and parent interviews*

The interviews took place in the schools or at home in the school year of 2007/8 (between October 2007 and July 2008). After a simple greeting, self-introduction, and brief explanation of the study, school staff members and parents were asked to explain their roles (school staff members) and their experiences of adolescents' asthma management (school staff members and parents). Parents discussed their views about their own children, whilst school staff discussed the adolescents they had observed in general. A list of the ten asthma management behaviours developed in chapter 3 was prepared in advance for the interviewer to ensure that interviewees were given the opportunities to discuss all behaviours. In parent interviews, if the young adolescents were with the parents, they were allowed to speak whenever they wished to.

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<sup>8</sup> Similar to the participants in chapter 3, the parent sample in this study is skewed towards a higher parental educational qualifications and more severe adolescent asthma status than the general population in the UK and in the county population where the participants were recruited from.

TABLE 5-1 Summary of profiles of schools, interviewed school staff, and parents

<b>School interview</b>	Number Mean $\pm$ SD	<b>Parent interview</b>	Number Median (IQR)
<b>School</b>		<b>Parent interviewee</b>	
With students $\geq$ year 7 only	9	Father	2
With students $\leq$ year 6 only	16	Mother	32
Others (including students $\geq$ year 7 AND $\leq$ year 5)	8	Father and mother	1
		Grandmother	1
State (non-independent)	17	Highest parent education level	
Independent	14	Less than GCSE	3
		Post-16 qualification	6
Boys' school	6	Post-18 qualification	6
Girls' school	5	University	11
Mixed school	22	Postgraduate degrees	8
		Unknown	2
Boarding school	6		
Non-boarding school	27	Adolescent gender (boy/girl)	17/19
		Adolescent age	11 (10,12)
Mainstream school	32	Adolescent asthma medication	
Special school	1	No medication	1
		Reliever only	12
1 interviewee only	26	Reliever and low dose preventer	16
>1 interviewees	7	Higher level of medication	7
		Adolescent participated? (yes/no)	24/12
Total	33		
<b>School interviewees#</b>			
Head / deputy head teachers	3		
Teachers	14		
Teaching assistants	3		
School nurses or first aiders	16		
Matrons	2		
Total	38		

\*IQR: interquartile range

#one or more than one interviewee in each interview

The interview was designed to be flexible for school staff and parents to share their own experiences, but it was also intended to allow the researcher to contribute to the experiences or the interpretation of the experiences (Rapley, 2004; Rubin and Rubin, 2005; King, 1996). For example, an interviewee might think that asthma management was only needed when there were acute asthma attacks, and the interviewer was allowed to explain that young adolescents with asthma were “still with asthma” even when they did not have asthma attacks. The feasibility of the interview protocol was tested in pilot studies with one primary school, one secondary

school, one independent college and two families. Interim analysis was conducted during the data collection to examine the feasibility of the protocol<sup>9</sup>.

*Dialogue units: the unit of analysis*

All interviews were tape-recorded and transcribed by the interviewer. Nonverbal communication was not recorded unless it was needed for clarifying the content (e.g. being sarcastic). All transcripts were segmented into *dialogue units*, which were the shortest self-explanatory contexts, and usually consisted of several sentences. All dialogue units were numbered and listed in Microsoft Excel® with the exact sequence as in the transcript, so that one could still read the context while individual dialogue units were inspected. The dialogue unit was the smallest unit of analysis, and the interviewee profiles (table 5-2) were readily available in the database when the data were analysed.

TABLE 5-2 Variables in school and interviewee profiles

Category	Variables
<b>School staff interviews</b>	
General School profile	School ID; school age range; number of school pupils on roll; pupils on roll per year (school name and school area were encrypted)
School type	Boarding school; private school; special school; single sex/mixed school
Interview	Interviewee (identity); the time of interview; the duration of interview
<b>Parent interviews</b>	
Parent variables	Parent identity (e.g. father); parent education level
Adolescent variables	Age; gender; medications
Interview	Time of interview; duration of interview; presence of the adolescent in the interview

<sup>9</sup> Interim analysis was conducted when data were collected from 18 schools and 18 families. The results provided feedback for the interviewer to consider the strengths and weaknesses in the interview protocol. Although the interview protocol remained unchanged, the first few interviews were more exploratory. As the interviews progressed, the interviewer was able to use more common language with the interviewees, and less time was spent in understanding the school contexts.

### *Mixed deductive and inductive thematic analytical approach*

The first step of analysis was deductive. Criteria were developed from the theories (reviewed in chapter 2) to define the keywords in the research questions. Specifically, asthma management was limited to the ten asthma management behaviours, and the social environment of asthma management, therefore, was defined as the behaviours and activities of others and the relationships with others that supported or hindered the ten asthma management behaviours. Zero, one or more *open codes*, ideally simple phrases, were generated from each dialogue unit by answering the research questions with the dialogue units (Silverman, 2005). Open codes had to be the relevant answers to the research questions as defined by theories. For example, if the purpose was to describe the peer-related social environment of asthma management, the open codes had to describe the behaviour and activities of peers and the relationships with peers that supported or hindered the ten asthma management behaviours. After open coding, themes were generated from open codes. The theme coding in this study followed Grounded Theory (Glaser and Strauss, 1967)<sup>10</sup>, which emphasises *inductive reasoning* and *constant comparison*<sup>11</sup>. To describe the process practically, conceptually similar open codes were grouped into one theme and given the name of an abstract concept that covered the *commonality* of open codes (analytic induction). The names of themes were not confined to terms used by respondents or theories. Open codes under different themes were compared to assess the *uniqueness* of the themes (constant comparison). Themes were allowed to be related to one another as long as they had unique properties in their definitions. The concept of commonality and uniqueness is similar to *sensitivity and specificity*,

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<sup>10</sup> However, the approach taken in this research was not identical with “classic Grounded Theory.” In a typical Grounded Theory method, theory is expected to be driven primarily from the data, while in the current research, the analytical process was substantially informed by assumptions and theories.

<sup>11</sup> The aim of inductive reasoning is to generalise the results to a context wider than the sample. Therefore, concepts that can be generalised to different open codes were abstracted. On the other hand, constant comparison kept the themes concisely defined, i.e. the simplest (but not over-simplified) structure can describe the richest information..

two widely applied concepts in quantitative studies (Feurman and Miller, 2008; Jouannic et al., 2004; Cuijpers et al., 2007). As one tries to maximise the commonality of a theme across all open codes, the definition becomes too generalised so that the uniqueness of a theme is lost. To solve this problem, the number of themes that answered each research question was set between two and five.

### 5.3 Adults' knowledge and understanding of asthma management

#### *General properties of knowledge and understanding of asthma management*

Firstly, adults' knowledge and understanding of asthma management were explored. There were 1791 dialogue units distributed in ten asthma management behaviours (table 5-3). Dialogue units from school staff interviews and from parent interviews were pooled before open coding and theme coding, and therefore the meanings of themes were consistent in both types of interviews. As a result, adults know and understand young adolescents' asthma management behaviours through *observation* and *recognition*. Adults *observe* how and how much the asthma management behaviours are enacted, and *recognise* why the behaviours are enacted.

TABLE 5-3 Descriptive analysis of dialogue units\*

<b>Asthma management behaviour</b>	<b>Number of dialogue units (%)</b>
1. using inhaler when asthma attack	*638 (36%)
2. telling adults when not feeling well	
3. keeping inhaler at hand	
4. using peak flow meter as planned	77 (4%)
5. using preventive medicine on time	97 (5%)
6. taking care on cold days	139 (8%)
7. avoiding air pollution or smoke	237 (13%)
8. staying away from others who have a cold	132 (7%)
9. taking part in physical activity	231 (13%)
10. warming up and down	75 (4%)
<b>Total</b>	<b>1791 (100%)</b>

\* occurrences of #1-3 are combined due to highly overlapping themes. One dialogue can be coded into one or more asthma management behaviours.

#### *Classification of asthma management behaviours by observation and recognition*

To describe adult observation and recognition of asthma management behaviour, the open codes between data from school staff interviews and from parent interviews were compared one by one from the first to the tenth asthma management behaviour. Therefore, how or how much each asthma management behaviour was observed by school staff and by parents were compared qualitatively from the data, and then how or how much each asthma management behaviour was recognised by school staff and by parents were compared. The results were interpreted by the interviewer<sup>12</sup>, and the observed-ness and the recognised-ness of ten asthma management behaviours were judged as binary variables (observed/unobserved and recognised/unrecognised), which classified the ten asthma management behaviours into four categories: observed-recognised, observed-unrecognised, unobserved-recognised, and unobserved-unrecognised (table 5-4).

TABLE 5-4 Thematic structure of asthma adherence knowledge

	School staff	Parents	Consistency
<b>Acute Exacerbation behaviours</b>	Observed	Observed	Yes
using inhaler when asthma attack	Recognised	Recognised	
telling adults when not feeling well			
keeping inhaler at hand			
<b>Chronic Medical behaviours</b>	Unobserved	Observed	No
using peak flow meter as planned	Recognised	Recognised	
using preventive medicine on time			
<b>Trigger avoidance behaviours</b>	Observed	Observed	Yes
taking care on cold days	Unrecognised	Unrecognised	
avoiding air pollution or smoke			
staying away from others who have a cold			
<b>Physical activity management</b>	Observed	Unobserved	No
taking part in physical activity	Unrecognised	Unrecognised	
warming up and down			

*Medical behaviours: acute exacerbation behaviour and chronic medical behaviour*

It was not surprising that the three acute exacerbation behaviours were all observed and recognised by school adults and parents -- young adolescents had

<sup>12</sup> The interviewer (also the researcher) had the richest experiences with the data and the context of the interview. Although these may be subject to interpretation bias, every attempt was made to maximise the authenticity of the data.

asthma attacks both at school and at home, and most school staff would notice when a student was having an asthma attack and know how to react when a student had an asthma attack. By contrast, the two chronic management behaviours related to daily asthma medication were observed and recognised only by parents, and were not observed (though they were recognised) by school staff -- most school staff reported that these behaviours usually took place at home, and therefore (apart from some boarding schools) school staff did not know about individual students' adherence to chronic medication behaviours. Compared to school staff, parents had good knowledge about their young adolescents' adherence to chronic medication behaviours, although they were not always active in encouraging this adherence. As seen in table 5-5, full adherence to peak flow meters or preventive medications is not frequently seen.

TABLE 5-5 Variations in adherence to chronic medical behaviour (parent interviews)

Themes	Variations	occurrences
<b>Peak flow meters</b>	With peak flow meters	12
	Regularly	1
	Only when symptom is severe	5
	Not using it	6
	Without peak flow meters	9
	No information	15
	Total	36
<b>Preventive medicine</b>	With preventive medicine	26
	Regularly	14
	Only when symptom is severe	11
	Not using it	1
	Without preventive medicine	6
	No information	4
	Total	36

*Life style management behaviours: trigger avoidance and physical activity*

The five non-medication behaviours (life style management behaviours) were consistently not recognised as a part of asthma management by school staff and parents. This did not mean that these behaviours were not encouraged in the school –

applied to young adolescents *with and without asthma*, they were thought of as a part of general health behaviours for everyone. For example, school staff cared about students' participation in physical activity, but they did not think it was an issue specific to those with asthma. They were observed by school staff, but the difference between young adolescents with and without asthma in these issues was usually small.

By contrast, only the three trigger avoidance behaviours were observed by parents. Unlike school staff, some parents did pick up that certain factors triggered asthma (e.g. catching a cold, physical activity), but trigger avoidance was still not classified as being well recognised because they were conceived of as a second-line management only for situations where the reliever inhaler was not useful. Physical activity behaviours, on the other hand, were not observed and not recognised by parents. Compared to trigger avoidance behaviours, adolescents' physical activity was relatively not observed at home. Meanwhile, many parents were only concerned about whether or not young adolescents were well looked after when they had asthma attacks in school, but participation in physical activity and warming up was rarely of concern. Some young adolescents who participated in the interviews reported that they were not given as many opportunities as others in sports even when they performed as well as others. These feelings were not usually recognised by parents until the interview. Young adolescents in the interview also reported that they did not tend to warm up in un-structured activities, including playing at home; some young adolescents felt their warm-up at school was physically so difficult that it triggered their asthma very easily. These situations were also not usually disclosed to parents. Therefore, parents' concerns about physical activity were primarily a concern in acute exacerbation management, but not participation in physical activity *per se*.

### *Summary and discussion*

To summarise, the qualitative results in this study suggest that adults' knowledge

and understanding of young adolescents' asthma management is "biased" primarily towards medical behaviours, and school adults particularly focus mainly on relieving asthma attacks. Although life style behaviours are observed by some adults, they are generally not recognised as a part of asthma management.

Although controller medication (chronic asthma management) only represents one aspect of asthma management, it is widely considered as a primary target of child and adolescent asthma adherence in the literature (van Dellen et al., 2008; Bokhour et al., 2008). There have been several interventions designed to improve children's life style non-medical asthma management, but adherence to medical and non-medical (or behavioural) regimes has rarely been included simultaneously in a single framework, especially in the school (Wolf et al., 2002; Chen et al., 2007a; Utz et al., 2008). In this chapter, qualitative results suggested a multidimensional feature of adults' knowledge and understanding of asthma adherence – what was observed was not necessarily recognised as asthma management, and what was recognised was not necessarily observed or monitored. From this perspective, the conceptual link between asthma and asthma management other than acute exacerbation management for school staff was surprisingly weak. This is consistent with previous literature where most school staff were not aware of asthma management, or did not think of asthma attacks as a problem as long as the symptoms could be relieved (Williams et al., 2008; Snow et al., 2005). Therefore, it might not be appropriate to assume that all aspects of asthma management are supported in the schools. On the other hand, parents' knowledge and understanding of young adolescents' asthma management other than controller medication is also under-represented in the literature (McQuaid et al., 2005; McQuaid et al., 2001). In this study, parents seemed to have more knowledge than school staff in relation to recognising asthma management behaviours. However, the critical weakness of parent reports seemed to be their limited observations on adolescents' school life so that some aspects of asthma management were unknown to them.

## 5.4 Adult-related social environment of asthma management

Having discussed the limitations of adult observation and recognition of young adolescents' asthma management behaviour, the adult-related social environment was explored by generating themes that described the activities and behaviour of parents and school staff or the relationships with parents and school staff that supported or hindered young adolescents' asthma management. As mentioned, the themes should describe the commonality of dialogues (or open codes) within a theme and the uniqueness which distinguished it from dialogues in other themes. Meanwhile, adult and school staff perspectives were compared within each theme. Verbatim quotes are used and interpreted to clarify the themes. Quotes from the transcripts are *italicised*, followed by corresponding serial numbers of the dialogue units (for easy retrieval). In a quote, words in parentheses ( ) were spoken by the researcher, and words in brackets [ ] are memos that help readers to understand the dialogues:

### Example

*Mother of a 10 year-old girl with asthma*

*“(what about the brown one [the preventer medicine], do you need to remind her?)*

*Mother: yeah, because she has always forgotten to take them. (she doesn't remember or she is not happy)”*

*Child: I sometimes remember.*

*Mother: I think this much she is not very keen on them. They don't like the green inhaler. You don't like to taste the green more.*

*Child: the brown is all right” (#51210)*

( ) spoken by the researcher  
[ ] memos

#51210: serial number for  
easy retrieval from the data

As a result, adults supported or hindered young adolescents' asthma management through *instruction/regulation, empowerment, and school-parent interaction* (table 5-6).

TABLE 5-6 adult-related social environment

<b>Theme</b>	<b>Instruction and regulation</b>	<b>Empowerment</b>	<b>School-parent interaction</b>
<b>Description</b>	Direct actions to support adolescents' asthma management	Enabling young adolescents to be sensitive to their health and to make well-informed decisions; characterised by the shift of responsibility to young adolescents	The degree and the ways to which school staff and parents receive messages from each other, react to messages from each other and deliver messages to each other
<b>Dialogue units (%)</b>			
Within school interview*	616 (58%)	188 (18%)	230 (22%)
Within parent interview*	120 (30%)	202 (50%)	83 (20%)
<b>Examples</b>			
<b>School staff</b>	<p><b>Medical behaviours</b> Inhaler policies Being aware of students' asthma status Providing advice in asthma management</p> <p><b>Life style behaviours</b> Keeping students inside when the weather is cold Warming up and down during exercise Supporting students who wish to quit smoking</p>	<p><b>Medical behaviours</b> Respecting children's decisions in asthma attacks</p> <p><b>Life style behaviours</b> Teaching knowledge about healthy lifestyles Campaigns that are pro-physical activity and anti-smoking</p>	<p><b>Medical behaviours</b> Following parental instruction in managing asthma attacks Informing parent children's asthma status for further instructions</p> <p><b>Life style behaviours</b> (lack of evidence)</p>
<b>Parents</b>	<p><b>Medical behaviours</b> Reminding children to use preventer inhaler Reminding children to keep inhaler at hand</p> <p><b>Life style behaviours</b> (lack of evidence)</p>	<p><b>Medical behaviours</b> Training children to use inhalers</p> <p><b>Life style behaviours</b> Listening to children's life stresses about asthma management</p>	<p><b>Medical behaviours</b> Filling in health forms Reacting to school concerns</p> <p><b>Life style behaviours</b> (lack of evidence)</p>
<b>Perspective Comparison</b>	Parents are more inclined to medical behaviours Punishment is seen in school staff-related environment	Parents know more about children's thoughts and feelings Less empowering strategies were used by parents	Parents are responsible for raising issues, but they are not as proactive as what school staff members expect. Parents wish to show trust to school staff.

\*a dialogue unit can be coded into zero, one or more than one theme

### *Instruction and regulation*

Parents and school staff perceived that they supported young adolescents' asthma management primarily via *instruction and regulation*, which are direct actions to facilitate young adolescents towards asthma management behaviour<sup>13</sup>. A distinct feature of instruction and regulation from other themes (introduced later) is its *goal-directivity* -- adults have decided the right way to do, and make attempts to direct the adolescents towards the behaviour<sup>14</sup>. There was a range of content of school and parental instructions or regulations (table 5-6), among which school inhaler policy appeared to be a major topic (table 5-7). In the adult-adolescent relationships as perceived by the interviewees, young adolescents were usually expected to follow instructions and regulations regardless of the existence of external reinforcement or punishment.

The prototypic instruction/regulation activities of the school staff members were simple -- telling students what to do. This is especially seen when the medical condition was apparently beyond what young adolescents could cope with.

#### *(A) health manager, secondary school*

*“So he is looking short of breath and looking as if he has trouble with a bit pallor, you know, generally describing symptoms, I would suggest they take their inhaler again, and again and again, until he really can't take anymore. Then I usually phone it to get them home or to the general practitioner or to the hospital to get them looked after properly. But sometimes I'd say they didn't have an asthma attack, and there isn't real symptom of breathing difficulty, so I maybe just observe them for maybe an hour and send them back to their school because they are actually okay.” (#6860)*

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<sup>13</sup> From this point of view, it is similar to the *specific social support* discussed in chapter 2

<sup>14</sup> From this point of view, instruction and regulation also describes a type of the adult-adolescent relationships, or a characteristic of *social capital*, as discussed in chapter 2.

TABLE 5-7 School inhaler policies

School inhaler policies	
<b>Inhaler policy</b>	
<b>Inhaler in classroom</b>	inhalers are kept in classroom with teachers or in cupboards
<b>Inhaler in special room</b>	inhalers are kept in medical room or in reception desk
<b>Inhaler kept by children</b>	inhalers are kept with students in bags, lockers or drawers
<b>Spare inhaler in school</b>	inhaler kept by students but a spare inhaler in special room
<b>Considerations</b>	
<b>Student maturity</b>	Does the policy require students to be aware of their asthma symptoms and to be responsible for keeping their inhaler and not losing it?
<b>Class structure</b>	Does the policy require a consistent class structure? As in most primary schools, everyone stays in the same classroom every day, and it would not be possible in most secondary schools.
<b>School staff involvement</b>	Does the policy require more loadings on school staff, such as keeping inhalers and checking the expiry date of inhalers?
<b>Parent cooperation</b>	Does the policy require special communication with parents, such as asking parents to send in new inhalers and information about the rules of inhaler use?
<b>Relationship with students</b>	Does this policy require children to feel comfortable raising issues to adults? Students might feel inconvenient or uncomfortable to tell adults when they need inhaler.

Similar to school staff, parental instruction and regulation was often delivered by telling adolescents what to do, frequently referred to as “reminding”:

*Mother of a 10 year-old girl with asthma*

*“(what about the brown one [the preventer medicine], do you need to remind her?)*

*Mother: yeah, because she has always forgotten to take them.*

*(she doesn’t remember or she is not happy?)*

*Child: I sometimes remember.*

*Mother: I think this much she is not very keen on them. They don’t like the green inhaler. You don’t like to taste the green more.*

*Child: the brown is all right*

*Mother: the brown is all right, but we change the brand, and you are not very keen on that one, though. So I have to do that reminding with the preventers. She understand why she has to have them, you just not very good at... taking it as I tell you to.” (#51210)*

The mother sensed that the girl was not very keen to use the new (green) inhaler, and had to “remind” her to use it regularly. In other words, the adolescent was reminded not only when she forgot, but also when she did not want to do it. Although the term “reminding” was being used, there was usually a mutual understanding of expectations that adolescents should follow the instructions.

Sometimes, however, young adolescents did not follow the instructions, and the school staff had to use psychological interventions, such as punishment:

*Health manager, secondary school*

*“They are trying quite hard to let them to do it [let students who do not participate in sports to do sports]. You know they’ll get sanctions. They’ll get detentions. It’s... they tried very hard to get them to do PE, and the students, if not want to do it, will work very hard not to do it.” (#9140)*

Parents and school staff were concerned with different issues in their daily activities of instruction and regulation. Compared to school staff members, parents instructed or regulated young adolescents more frequently in medical behaviours, and rarely in life style behaviours. By contrast, school staff members instructed and regulated across medical and life style behaviours, but were less involved with chronic medical behaviours. Some school staff mentioned that punishment or external reinforcement was used. By contrast, there is no evidence in this study suggesting that punishment or external reinforcement was used at home for asthma management. Nevertheless, both parents and school staff members were actively engaged in instructing and regulating activities and directing young adolescents towards asthma management behaviour.

*Empowerment*

As adolescents mature, adults are less able to instruct and regulate adolescents on everything. Therefore, adults have to *empower* the young adolescents, i.e. to enable them to be sensitive to their health and to make well-informed decisions as to what is best for them. In practice, empowerment is characterised by shifting of responsibility from adults to young adolescents and building the decision-making competence in the responsibility shift. When young adolescents started to control their lives, they have personal preferences on the ways they choose to live in. Therefore, some young adolescents underwent stressful events when they wanted to manage asthma while they still wished to enjoy their social lives. Compared to instruction and regulation, adults empowered adolescents by providing support for coping with these stresses, rather than directing the young adolescents towards asthma management.

We have seen in the instruction and regulation where the prototypic adult support was delivered via telling adolescents what was the best to do. In empowerment, however, the most prevalent type of adult support seemed to be delivered via sharing their knowledge with adolescents. Adolescents' compliance was not the only issue -- their knowledge, thoughts, attitudes and preferences were usually considered:

*Head teacher, primary school*

*“Like anything like we washing hands, if you say to them you must wash your hands after toilet or before lunch, I mean just leave it, they might do it on that day but they won't do it the next day. If you do the training, this is something on your hands, this is something that might happen, then it is likely they know why it is important. So you must do every time, and more likely you can have an effect. They need to be really, under the training program, that's what they need to have. And I have to say we don't have the training program for asthma. The teachers, we have had people to come to teach about it, but it is not something we specifically do it. (because not*

*everybody has it?) Because not everybody has asthma” (#530-540)*

*Mother of a 12 year-old boy*

*“Although other people can see how his... no one can really see the tightness of his chest. So I’d make very clear to him from early age that he’s got to manage his asthma. And so you’ve been quite responsible. I mean there are occasions I was next to him and he was like [imitate wheezing] I’ll say “can you listen to yourself” he goes yeah. I’ll take my thing. Generally you are quite, you are very good at doing this. In the end, it is your problem. So you’ve got to deal with it really.” (#42260)*

Knowledge sharing might be a prevailing empowering practice perceived by adults, but it was by no means the only practice. The interviewees described many more activities other than knowledge sharing, some of which were not explicitly perceived as a part of empowering practice. Compared to school staff, parents seemed to have more “quality time” with young adolescents, and have more knowledge about young adolescents’ attitudes and preferences. To help the adolescents to enjoy their social life, parents tended to provide emotional support when adolescents found it difficult to manage asthma:

*Mother of an 11 year-old girl with asthma*

*“my children are very much like... because one was actually offered cigarette one day. You never guess what happened to me at the school today. Oh my god she’s offered drugs in the playground or something you know, you just don’t know. She said it is someone offered me a cigarette, I still don’t know what to say. I said you would be stupid if you say yes. Well can you? So hopefully, she is one of those smart girls who don’t smoke.” (#45350)*

*Mother of a 12 year-old girl with asthma*

*“Mother: because she [the dance teacher] has actually pushed her. In the dance lesson she had too much, and she ended up being not able to, hardly breathe.... I don’t think the teachers’ got time to worry about individuals. ... I mean you are getting there, aren’t you? but it still makes a difference to how she dances compare to the next person. So it’s quite, but it’s something she’s got to learn it herself. The teacher keeps saying you’ve got to keep breathing, you’ve got to get the rhythm, have you breathe in right. ... but I mean the other thing about that is she is now more able to say I actually can’t do anymore. That’s as much as I can push myself, which makes her become a bit agreement [i.e. more capable of expressing her opinions and reaching agreement with the teacher] now. Say we have a lesson and just one on one, that’s what you are going to do, isn’t it?”*

*Child: yeah*

*(do you actually feel that I can say now to the teacher?)*

*Child: yeah*

*Mother: yeah she was not struggling. You are not a person to tell one or people, no, when you are ... now she is getting better. But I have to say she’s dealt it on her own now. It’s not so bad anyway, but she’s never been a person who comes and says I don’t feel very well or my chest is... sort of. (#46660-46680, 46940)*

In contrast to parents, school staff members seemed to be more resourceful and more strategic in empowering young adolescents by providing alternative solutions to asthma management difficulties, especially when there was a school nurse in place:

*Nurse, private secondary school*

*“(has asthma been affecting their sports performance?) I mean one of our best runners, they had a triathlon on Sunday, and the boy that won is an*

*asthmatic, you know, is on irregular treatment, on irregular beclotide, and he actually came here. But he did have to come up here afterwards, but you know, they fully take part.” (#17230)*

The student, who had asthma, was excellent in triathlon. It was understandable that he chose to complete the race despite the fact that he had an asthma attack, which might have discouraged him from completing the triathlon. Instead, his achievement was fully respected by the school, and professional reassurance was given to support his breathing difficulties.

Both school staff and parents supported young adolescents through the period when responsibility for asthma management is gradually shifted from adults to adolescents. Besides knowledge-sharing activities, adults provide support that helps young adolescents to cope with the stress encountered in asthma management. Compared to school staff, parents seem to have the advantage in being more familiar with their thoughts and feelings, and hence provide emotional support in stressful events. On the other hand, school adults tend to be strategic in actually helping to solve young adolescents' own problems once a problem is defined. In both empowering situations, the goals and preferences of adolescents are respected and valued.

### *School-parent interaction*

*School-parent interaction* is the degree and the ways in which school staff and parents receive messages from each other, react to messages from each other and deliver messages to each other. Compared to instruction/regulation and empowerment, school-parent interaction is the activity *for* young adolescents but not *towards* young adolescents. Through school-parent interactions, adults may influence the ways of their instruction/regulation or empowerment and support asthma

management.

The pattern of school-parent interaction seemed to be different in relation to medical as opposed to non-medical behaviour, and the perceptions of school-parent interaction seemed to be different between parental and school perspectives. From the perspectives of school staff, one important aspect of school-parent interaction is *pro-activity*, or who is responsible for raising concerns. School staff members expected parents to play an active role in medical behaviours, and the schools followed parents' rules as much as they could. If there was a problem, the school would notify the parents and wait for further information. Of the three components in school-parent interaction (to receive, to react and to deliver), school staff received and reacted to parents' instructions, and delivered messages about students' asthma status to parents. Therefore, the school staff thought they could not help very much when parents were reluctant to share the information, or when parents thought it was not important to make efforts to share this information:

*Teacher, state secondary school*

*“(do parents think the school is sometimes ignorant about asthma?) I think what it is is that in primary school she's got these informal occasions where the mum can say to the teacher. And there is a lot of opportunity for this kind of discussion [in primary school], when here [in secondary school] it has to be an appointment or more formal telephone conversation. Probably it is a grey type of parents [i.e. not black and white, neither active nor passive], if they have seen you, they just go bla bla bla. That isn't happening because it doesn't [seem important enough for them to] actually make a phone call.”*

*(#5240)*

By contrast, parents did not always perceive themselves as playing an active role in the school-parent interaction. In fact they appeared somewhat inactive. In medical

behaviours, parents generally kept the school informed by filling in regular medical forms once in a while, and reacted to the school when they were contacted about asthma-related concerns, such as when young adolescents had asthma attacks. Parents rarely raised concerns proactively about asthma. Instead of emphasising pro-activity, parents seemed to emphasise *trustworthiness* as the important aspect of school-parent interaction. Although some parents admitted that they did not have as much information as they wished on their young adolescents' asthma in the school, they usually felt that schools were to be trusted or it was not the school's responsibility:

*Mother of a 9 year-old girl with asthma*

*“(would you expect the school teacher knows how to use the inhaler?)*

*Mother: well, or the nurse I suppose.*

*Child: we don't have a nurse.*

*Mother: you don't have a nurse?*

*Child: no*

*Mother: I didn't know that.*

*(who give you the inhaler?)*

*Child: well it is in the nurse's office, and all the people in the office help out  
(but would you expect people in the office would know)*

*Mother & child: yeah*

*(but they are not health professionals)*

*Mother: No. but also I suppose I know Daisy knows how anyway, so she can help herself anyway.” (#48910)*

When it came to non-medical behaviours or life style management behaviours, the interactivity between parents and schools seemed much weaker. From the perspectives of school staff, some felt that it was difficult to collaborate with parents, and that the lack of interaction between school staff and parents might cause further difficulties in facilitating life style management behaviours:

*(A) head teacher, state primary school*

*“(What if their parents smoke, how do they cope with this?) Well, they just realise, well I hope them realise that their parents are doing something wrong, maybe. (Maybe the parents would avoid smoking in front of them?) Um... And it is difficult because I don’t actually know whose parents smoke. (And it is not something we can do, to bring up in our conversation?) No. All we can do is say to the children, you should not smoke, or you should leave from other people who smoke.” (#380)*

*(B) teacher, state secondary school*

*“And not everybody, I mean I am generalising, but I mean the general trend, the parents would want to be more liberal and friendly, and not want to lose that relationship with the child. When somebody come to discipline, and parents want to... and they don’t want you to tell them how to do it, they say well you do it, if you tell them, I don’t want to get involved. We do have more, yes; there is a shift of responsibility.” (#15940)*

From the perspectives of parents, showing trust towards the school was still a major concern in life style management. Parents sometimes did not raise their concerns not because they did not care, but because they did not want to be labelled as a fussy mother or father. In other words, it was not perceived appropriate to show distrust towards the school:

*Mother of an 11 year-old girl with asthma*

*“So, if I say to them [the school] when she is going on the school trip, can you make sure she doesn’t get a cold and she gets wrapped up. I am seen to be a fussy mother. Do you understand what I mean? (Um) So it [raising concerns] becomes very difficult.” (#40260)*

Therefore, the responsibility of parents and the responsibility of school staff are sometimes “apples and oranges” -- they are not always compatible. Although both parties (school staff and parents) agreed that it was the parents’ responsibility to raise concerns and to decide on children’s asthma management, this did not result in parents being as proactive and competent as was expected by school staff. Quite the opposite, parents expressed the view that they should find the school trustworthy, which might stop them from being pro-active. Nevertheless, school-parent interaction represents one aspect of the social environment that influences asthma management in early adolescence.

#### *Brief summary of results*

According to the qualitative evidence derived from parent and school staff interviews, *Instruction and regulation* is the most direct way to express adult feelings and to help young adolescents in their asthma management. When children mature, however, they start to be responsible for their life and their health, and occasionally, they find it stressful to manage asthma when they want to enjoy their social lives. Through *empowerment*, therefore, adults share their knowledge and provide support that helps adolescents to cope with stress, thereby facilitating them in their ability to well-informed and competent decisions. Adult instruction, regulation and empowerment are also influenced by *school-parent interactions*, through which information is exchanged between parents and school staff to in order to inform activities and behaviour that support asthma management.

#### *Empowerment as a concept within the social environment*

In chapter 2, three concepts were introduced to describe a supportive family environment for young adolescents, among which *parental involvement* stands for

family life-sharing, *parental warmth* refers to an effective communication to reduce or to prevent family conflicts, and *parental autonomy support* is the authorisation of adolescent decision-making. Within the context of adolescent chronic illnesses, mostly from studies in diabetes, responsibility for disease care emerges in the literature as an important topic which overlaps the three concepts in the family environment. This knowledge helped to develop the study reported in this chapter.

What has not been reviewed so far is the concept of *empowerment*, which has been an extensively used keyword in health sciences over the past two decades (Loukanova and Bridges, 2008), but has not attracted much attention from theories in developmental psychology. Empowerment was used as early as 1986 in the Ottawa Charter for Health Promotion, where it was a process to *enable* people to control their health with autonomy (WHO, 1986). For example, if a rural village lacks medical resources, a non-empowering intervention aims to build hospitals and send doctors to increase local standards of medical care, whereas an empowering intervention aims to train local people so that they can have self-provided medical care on a long-term basis. The term “empowerment” has also been used in a broader, non-health social context, i.e. the process to enable a person to control their *life* (not just their health) with autonomy (Barak et al., 2008; Ben-Porat and Itzhaky, 2008).

*“Empowerment as a relational term is achieved when A acts towards B in order to support B in gaining better control over the determinants of her quality of life, and this acting of A towards B necessarily involves a minimising of A’s own ‘power’ or influence over B with regard to goal/problem formulation, decision-making, and acting, and B seizes some control over this situation or process.” (Tengland, 2008)*

The core concept of empowerment is the transfer of *power*, so that people have rights to decide what is good for them. In other words, the “empower-ees” could

control their self-defined quality of life, which is allowed to differ from empowerer-defined quality of life (Redman, 2007). However, it is simplistic to ask rural villagers to decide what to do without educating them -- Only when they are educated with skills and informed of possibilities can they make well-informed decisions. Therefore, empowerment is not the shift of power *per se*, but a facilitated process of self-reshaping towards independence (Aujoulat et al., 2008; Kato et al., 2008; Cooper et al., 2008). Therefore, compared to parental autonomy support and responsibility shift, empowerment may also be characterised by transfer of responsibility or transfer of the right of decision making, but it does not have direct concern on who makes the decision or who is responsible for enacting the decision (i.e. the behaviour). Instead, the direct purpose of empowerment is the *competence* of decision making and enacting.

Following this definition of empowerment, although transfer of knowledge and skills is usually seen in health empowerment intervention, an effective empowerment usually involves problem-solving skills and social skills. Problem-solving skills, including problem identification and an effective thinking process of decision making, have helped people to gain self-control and improve medical adherence in previous studies (Kang et al., 2008; Zoffman and Lauritzen, 2006). Social skills, such as stress coping strategies and communication skills, have also helped people to gain personal confidence and help-seeking ability in health management (Ducharme et al., 2006). Meanwhile, fostered social networking has proved successful in facilitating perceived social support in a training program for patients with AIDS in South Africa (Pronyk et al., 2008b). Recalling the literature on the peer environment reviewed in chapter 2, problem-solving skills and social skills have also been a major topic in adolescent peer relationships. Therefore, although empowerment (as a concept in health psychology) seems relatively new to the theories in developmental psychology, similar practices have been emphasised for the general young adolescent population. The findings of this study suggest a further generalisation of these practices towards a

social context broader than peer relationships, and it would be useful in future studies to confirm the benefits of social skills or social competence in the shift of asthma management responsibility in addition to the benefits in peer relationships.

### *Comparison between empowerment and instruction/regulation*

Although theoretically it seems reasonable to define empowerment and instruction/regulation as two different aspects of adult-adolescent interactions, it is not easy to distinguish the two concepts in the literature on health psychology. For example, despite the idealistic definition of empowerment, it is difficult to capture the right outcome of an empowering intervention. As mentioned, earlier empowering interventions emphasised the transfer of knowledge and skills in order to achieve a favourable predefined health outcome (Kato et al., 2008) -- this is not really distinguishable from a non-empowering intervention (i.e. instruction/regulation). To approach a theoretical justification, however, more and more interventions have been assessed with a wider range of outcomes, such as psychological well-being or standardised quality of life measures (Cooper et al., 2008; Pronyk et al., 2008a). Besides, sustainability of behaviour is frequently considered theoretically (philosophically) as a major strength of empowerment, but has not been consistently proved in the real world (Gine and Perez-Foguet, 2008). All the outcomes described above, nonetheless, primarily describe the *medical success* of an intervention, and may not capture the critical sense of empowerment (em-“power”). Investigating power transference usually requires a deeper understanding of the person, the environment and the relationships between them. Therefore, qualitative studies have been conducted to demonstrate the self-development of empowerees, but the findings have not been satisfactorily translated to quantitative assessment (Pronyk et al., 2008b; Luginaah, 2008; Utz et al., 2008). Transfer of knowledge and skills were only associated with medical outcomes, and transfer of power was only associated with personal confidence in disease management without additional benefits in medical

outcomes (Kang et al., 2008; Ducharme et al., 2006; Zoffman and Lauritzen, 2006). Therefore, the health literature has not provided sufficient evidence to enable us to conclude that empowerment is necessarily a better approach to health support than instruction or regulation.

Of course, the importance of empowerment seems self-evident in the particular context of this study. Compared to other health studies where responsibilities can be shifted after people are empowered, young adolescents have very limited choice in this responsibility shift – the responsibility will be shifted when they grow whether or not they are empowered to make well-informed decisions. This topic is still under-investigated in the literature of asthma management or other adolescent chronic illnesses, and further studies are required to define the best adult support for adolescent disease management.

#### *Differential roles between parents and school staff and parent-school interactions*

The results of this study confirmed the evidence in other literature in that parents and school staff share more similarities than differences in their relationships with young adolescents. They share similar patterns of interaction (instruction/regulation and empowerment) with young adolescents, and the developmental concerns in asthma management (responsibility shift in particular) apply to both parents and school staff members. These findings all suggest that our knowledge of adult-adolescent relationships in the family environment may also be generalised to the school environment.

However, the differential roles between parents and school staff are also worth discussion. In this study, school staff seemed more experienced and strategic in delivering interventions to *solve problems*, while parents seemed more privileged in understanding the real concerns of young adolescents, which may be a strength in

*defining problems.* Therefore, despite the similar “structure” of adult-adolescent relationships suggested in this study, their differential strengths and weaknesses should also be recognised. More importantly, the school-parent interaction, as a third theme that describes the adult-related social environment, might thus play a positive role in young adolescents’ asthma management by combining the strengths of both roles.

### *Summary*

Having recognised the literature of developmental psychology on the characteristics of a supportive family environment, the adult-related social environment was explored in this study by generating themes that described the activities and behaviour of parents and school staff or adolescents’ relationships with parents and schools staff that supported or hindered young adolescents’ asthma management. As a result, this social environment was described with *instruction/regulation, empowerment and school-parent interaction.* This result added to the knowledge of the impact of the adult-related social environment: Firstly, instead of concerning autonomy granting (adult autonomy support) or responsibility shifting, empowerment addresses the development of *competence* to make decisions and to take responsibilities. Secondly, in contrast to instruction/regulation, the development of competence in empowering support allows adolescents to made informed decisions for themselves, rather than follow instructions and regulations decided by adults. Although there is no evidence suggesting empowering is always better than instruction and regulation, the natural progress of responsibility shift in adolescents seems to urge empowerment to take place. Thirdly, the differential roles of parents and school staff members were addressed. School staff seem to be more experienced in solving problems, while parents may be privileged in life-sharing and defining problems for young adolescents. Overall, these findings suggest that a modified theoretical framework might be required to address the adult-adolescent relationships

when asthma management behaviour, but not general adolescent behaviour, is concerned.

### **5.5 Adults' views on the peer-related social environment of asthma management**

After the views of parents and school staff on their relationships with adolescents have been discussed, this section considers the views of parents and school staff on the behaviour and activities within adolescents' peer relationships. As expected, there were fewer data in this study regarding the peer-related social environment than the adult-related social environment. Compared to 1047 dialogue units of school staff environment in school staff interviews and 404 dialogue units in parent interviews, there were only 261 dialogue units in school staff interviews and 175 dialogue units in parent interviews concerning the peer environment. Not surprisingly, the themes generated to describe the peer-related social environment were very different from the adult-related social environment. They were "immediate support," "peer attention," and "peer distraction" (table 5-8).

TABLE 5-8 Peer-related social environment of asthma management (adults' view)

Theme	Immediate support	Peer attention	Peer distraction
<b>Description</b>	Peers' explicit support in asthma management or facilitating asthma management	Children feel anxious under peer attention in a small group or a larger crowd, and sometimes try to avoid this attention	Following peers' rules without feeling stressed
<b>Dialogue units (%)</b>			
Within school interview*	57 (22%)	113 (43%)	116 (44%)
Within parent interview*	28 (16%)	83 (47%)	94 (54%)
<b>Examples</b>	<p><b>Medical behaviours</b></p> <ul style="list-style-type: none"> <li>Helping to get the inhalers in an asthma attack</li> <li>Borrowing inhalers from one another in an asthma attack</li> <li>Helping to seek adult help in an asthma attack</li> <li>Taking care of schoolwork in school absence</li> </ul> <p><b>Life style behaviours</b></p> <ul style="list-style-type: none"> <li>Providing emotional support in physical activity</li> <li>Making close friends with children who have asthma</li> </ul>	<p><b>Medical behaviours</b></p> <ul style="list-style-type: none"> <li>Having people know he/she has asthma</li> <li>Using spacers while other people do not</li> <li>Having asthma attacks in public</li> </ul> <p><b>Life style behaviours</b></p> <ul style="list-style-type: none"> <li>Keeping away from friends who have flu</li> <li>Wearing coats while others do not</li> <li>Refusing a smoking invitation among peers</li> <li>Having asthma attacks in physical activity</li> <li>Having adult attention in physical activity</li> <li>Performing worse than peers in physical activity</li> </ul>	<p><b>Medical behaviours</b></p> <ul style="list-style-type: none"> <li>Forgetting to use inhalers when busy playing with peers in asthma attacks</li> <li>Not wanting to make a fuss by asking adults for inhalers</li> </ul> <p><b>Life style behaviours</b></p> <ul style="list-style-type: none"> <li>Feeling cool to be a smoker</li> <li>Forgetting to wear warm clothes when busy playing with peers</li> </ul>

\*a dialogue unit can be coded into zero, one or more than one theme

### *Immediate support*

This theme refers to peers' immediacy (or approachability) to offer support in asthma management and/or facilitating asthma management. Young adolescents are almost always surrounded by peers, and peers are the most likely immediate people to offer support when an adult is not around or not approachable. Therefore, many young adolescents would tell their friends when they were unwell or when they need help in asthma management behaviours:

*Mother of a 14 year old boy with asthma*

*“(but it is up to him [to use the inhaler]? The teacher wouldn’t notice?) I think if the symptom would go extremely bad I think the teacher would kind of see it, you know. Or maybe somebody would have pointed it out. (do you think if the symptom is not very bad, he wouldn’t tell people?) I think maybe he would tell his friends. They are at the kind of age. Now he would try to talk to his mate and maybe... then the teacher.” (#47520)*

In addition, peers do not only provide immediate support for asthma management *per se*, but also provide support in their social life in order to facilitate their asthma management, for example, young adolescents with asthma sometimes understand each other more than medical aspects in asthma management. Some young adolescents with asthma made good friends and look after one another in their social life:

*A 10 year-old girl with asthma*

*“like Amy she is asthmatic as well, and we help each other with the cycling. Because some other kids won [the cycling race]and make you [feel bad]... but we know we shouldn’t because we’ve got asthma. Sometimes we run a little bit, but...” (#51140)*

The girl and her friends thought they did not perform well in cycling because they had asthma. They sympathised with each other so that they could at least enjoy sports. Therefore, peers not only provide support in asthma management, but also help in a wider context that makes their asthma management less difficult.

### *Peer attention*

Although some young adolescents do tell their peers and seek help from their peers, others seem to feel particularly anxious when they are the focus of attention in a small group or a larger crowd. To avoid this anxiety, they tend to follow the general trend, or “play safe,” so that they do not appear to make a fuss in a crowd. If they *perceive or appraise* that their asthma management behaviour is likely to attract peer attention, the way they cope with the anxiety might determine how much they adhere to the asthma regimes. Because their perceptions or appraisals of peer attention are important, the kind of situation which causes peer attention might be idiosyncratic. Therefore, although examples of peer attention-related influence could be found in three types of behaviours (acute exacerbation, trigger avoidance and physical activity, see table 5-8), most examples did not apply to all young adolescents, and not all young adolescents would choose to cope with the stress simply by avoiding the peer attention. Therefore, compared to the previous theme (peer immediate support), peer attention describes a peer-related influence less about peers’ explicit attitudes on asthma management, but more about young adolescents’ perceptions (or interpretations) of the peer environment.

Medical behaviours, such as using spacers or inhalers, asking for inhalers, or even admitting having asthma would sometimes place young adolescents under the spotlight:

#### *Teacher, primary school*

*“I think year 5/year 6 are much more restrained about asking for inhalers when they need them. Because they still don’t want to look, in front of their friends, as they’ve got a problem. So they tend to not react it in a way that maybe they would when they are younger.” (#1280)*

However, this anxiety related to peer attention also happened in non-medical asthma management, such as smoking behaviour:

*Teacher, primary school*

*“But, certainly I have got a teenage daughter. She doesn’t smoke. But she tends to be, a lot of friends smoking she finds it. And she wishes they didn’t. ... But you know, it is not, I mean, depends on how much they are affected by their peer pressure. How strong they feel. I’d say I am lucky that my daughter is quite strong about it, but I know some children haven’t got enough strength to be able to say, look, you might have chosen that, but I am not going to. ... That has to do with the language and sort of the intelligence skills, isn’t it?” (#1570, #1610-1630)*

In this small group, the social rule was pro-smoking. This produced a stressful situation because young adolescents might feel obliged to follow social rules in this group even when they did not want to. They might try to avoid the stress by accepting the invitation to smoke or by leaving the group. Choosing to stay in the group while staying anti-smoking appeared to require additional psychological strength and communication skills. More importantly, all these considerations were not necessarily related to peers’ explicit attitudes specifically towards asthma management.

This is not to say that peer attention-related social anxiety is always stronger in a small group than among a larger crowd. Instead, young adolescents also seem to be sensitive to a wider crowd:

*11 year old boy with asthma, who tended to have asthma attacks when he was angry or when he was nervous in football matches*

*“probably like in a football match sometimes I get a bit embarrassed. (what do other people react?) they are fine about it, but like that’s when like*

*everybody stare at me kind of things when I am taking it. (is it more about people who know you or who don't know you?) It's more about people who don't know you kind of thing. They could think it sometimes a bit weird, but... (people who know you would understand.) yeah.” (#44470-44480)*

In this example, although people usually acted as if they were fine about his asthma attack, he still felt stressed because he perceived that they might find his attack a bit strange. Therefore, he was not sensitive to the wider crowd *per se*, but his uncertainty as to the perceptions of the wider crowd.

### *Peer distraction*

Although peer attention or peer attention-related stress seemed to provide a classic explanation of the impact of the peer environment, it does not explain the complete picture. There were times when young adolescents simply follow peer rules without being aware of any peer stress – this is usually referred to by adults as “being distracted from asthma management by peers.” Similar to peer attention, peer distraction is also a peer influence with relatively less emphasis on peers’ explicit attitudes towards asthma management, but more importantly, compared to peer attention, peer distraction does not usually involve young adolescents’ perceptions or interpretations of the peer environment:

*Teacher, state secondary school*

*“(So do you think it is not cool or because they are busy and forgot it [to bring their coats on cold days]?) No, it's not cool. My daughter leaves the house with the coat on, catching up when later in the day and the arms are out there and the coat is in the bag. So they wouldn't [put on their coats]. I think they'd rather be ill.” (#4980)*

In this example, it was the consideration of being cool that dominated the girl's decision. Between un-coolness and illness, they would rather choose to be ill. In other words, young adolescents' rationality was distracted by perceived peer rules from making the "right" decision (as defined by adults). There was nothing wrong to conclude that "they want to be cool and they'd rather be ill." However, the phrase "they'd rather..." did not really fit -- in addition to using "they'd rather...", school staff and parents tended to use "they forget," "they wouldn't bother," or "they don't see the point":

*(A) health manager, state secondary school*

*"They'll say I got this kind of cough and my throat is really sore, and then I'll say well, if you didn't smoke this wouldn't be happening to you. You need to stop smoking. And then they just kind of "well well, but I don't smoke... well, I only have... you know, a lot of excuses about they don't have smoked much or they don't smoke at all or, see some of them are well educated they will understand it, but some of them just...yeah, they just don't see the point. Yeah, they don't see the connection. Yeah, we might have asthma, yeah, we might smoke, but actually, I am invincible because I am a teenager and you know, whatever." (#7130-7140)*

*(B) mother of an 11 year old boy with asthma*

*"sometimes he might forget [to use the inhaler], but he might have asthma, say he will come in feel difficult to breath today, I'll say do you think you need your inhaler, oh no, because his minds is on other things. You know whether it will be school, it will be school match, whatever, he can forget, and I would say, do your inhaler, oh yeah." (#44490)*

*(C) matron, special school*

*"(Do they not feel cold? Is it a fashion [to dress little in cold days]?) I think*

*it is a mixture. Some of them don't feel cold because they really aren't cold, because they are too busy doing other things they don't notice. For some of them it is not quite fashionable, it is not quite a thing to do; others because they can't find the jumpers.” (#5590)*

These scenarios are not exclusive to early adolescence -- mature adults may also have their minds occupied and make “irrational” decisions (as defined by others). However, when young adolescents were with adults, they were constantly reminded to take care of themselves; when they were with peers, having fun was at the forefront of their minds, rather than asthma. It seemed to be the simpleminded-ness that was behind the “they don't see the point” or “they forget” that made them susceptible to the cool- or fashion-madness. A sign of simple-mindedness was the low sensitivity to detect problems (e.g. asthma attacks), and low quality in their decision-making process. Therefore, being well-informed did not guarantee a well-informed decision. In many situations, young adolescents “could not be bothered” to consider other aspects of a decision, which might explain why their decisions were sensitive to peer interference.

#### *Brief summary and discussion of the results*

According to the qualitative evidence from the adult interviews in this study, although peers are not as mature as adults, they are close to young adolescents, and still provide *immediate support* to help in young adolescents' asthma management or facilitating asthma management. However, there are other activities in the peer environment that influence adolescents' asthma management without explicit expression of peers' attitudes towards asthma management *per se*. Sometimes young adolescents are aware of *peer attention* in a small group or a big crowd, as this may inhibit them from asthma management behaviour since this makes them feel different from peers. Meanwhile, they may also be *distracted by peers* and forget to consider

their asthma management.

Peer attitudes have been shown in the literature as having a great influence on children and adolescents' health behaviour (Hains et al., 2007; Chen et al., 2007a). Although immediate peer support is the most explicit way to express peers' attitudes towards asthma management, it may not be the only behaviour or activities of peers that influence the asthma management of young adolescents. In the current study, for example, peer attention reflects young adolescents' perceptions of peer attitudes (Armitage, 2005; Harakeh et al., 2004), while peer distraction reflects young adolescents' simpleminded-ness that makes them easily distracted from asthma management behaviour in the peer environment. Recalling the literature review in chapter 2, human behaviour is considered by behavioural psychologists as a manifestation of human reactions to the environment. Considering this theory, both peer attention and peer distraction describe young adolescents' interactions or relationships with peers that influence their behaviour.

The influence of peer attention on adolescent behaviour is commonly explained as a result of social anxiety (Anthony et al., 2003; Cartwright-Hatton et al., 2005). Sometimes referred to as "shyness" in childhood, social anxiety arises when we sense that we are being evaluated by people in social situations (or in public). The signs of social anxiety start earlier than 11 years old in 50% of patients who were diagnosed later in life as having (pathological) social anxiety disorder (Stein and Stein, 2008; Kroenke et al., 2007). Meanwhile, severe and functional-disturbing anxiety can also be frequently seen in adults who have awareness of some physical illnesses, such as stuttering and essential tremor (Schneier et al., 2001; Stein et al., 1996). From this perspective, this current study confirms previous research and suggests that young adolescents also consider peer attention and peer evaluation, especially when they have medical conditions.

By contrast, peer distraction has attracted less direct attention in the literature. However, “forgetfulness” has been frequently mentioned in qualitative literature as a “reason” for poor adherence in many studies (Penza-Clyve et al., 2004; Buston and Wood, 2000; Ayala et al., 2006; Rhee et al., 2008). A forgotten behaviour could be attributed to low motivation, low self-efficacy or negative attitudes, but there have not been many quantitative studies that explain how the concept of “forgetfulness” creates the gap between knowledge and behaviour. A closest example would be the “cue to action” in Health Belief Model (Essen et al., 1997; Glanz et al., 2002) -- cue to action is an environmental cue which helps to retrieve our memory that has not been realised as a resource to solve problems. In contrast to forgetfulness, distraction may exist when there are several thoughts or behaviours competing in our thinking capacity. It might be similar to McGuire’s Information Processing Theory, where *exposure (or exposure to information)* was considered as a pre-requisite step before information processing. For example, a pre-requisite step for a successful advertisement is to catch the attention of potential customers among hundreds of other advertisements that may be encountered within a day (McGuire, 1975). The concept of exposure in McGuire’s Information Processing Theory has been applied in health studies related to mass media and marketing strategies, especially tobacco advertisements (Flay et al., 1980; Moodie et al., 2008). This current study highlighted peer distraction as a possible dimension of peer-related social environment in asthma management, which might suggest the inclusion of cue to action (health belief model) and exposure (McGuire’s information processing model) into future asthma management interventions for young adolescents.

## **5.6 Summary and Conclusion**

In contrast to the previous two chapters where quantitative results demonstrated the relationship between asthma adherence and the social environment, a qualitative study is presented in this chapter to explore the characteristics of the social

environment of young adolescents' asthma management from adults' points of view. Firstly, how asthma management behaviour was *known and understood* by parents and school staff was explored. As a result, this knowledge and understanding of asthma management included not only how asthma regimes were adhered to (*observation* of asthma management), but also how the management behaviours were related to asthma control (*recognition* of asthma management). Parents observed medical behaviours (acute exacerbation management and chronic medication) more than life-style management (trigger avoidance and physical activity), while school staff observed all aspects of asthma management other than chronic management. Meanwhile, both adults had lower levels of recognition of life style management than medical behaviours.

Secondly, the adult-related social environment, i.e. the behaviour and activities of adults or the relationships with adults that may support or hinder asthma management in early adolescence were investigated. Although *instruction/regulation* is still one primary way of adult-adolescent interactions, the study identified the concept of *empowerment* from the literature in adult health studies as an enabling support in the shift of asthma management responsibility from adults to adolescents. Discussion was made to distinguish the concept of empowerment (enabling autonomy or enabling decision-making competence) from adult autonomy support (granting autonomy or shifting decision-making dominance) and responsibility shift (shifting duties). Meanwhile, despite the similar patterns of adult-adolescent interactions observed in the family and the school contexts, the strength of parents in problem-defining and the strength of school staff in problem-solving suggest differential roles for the two types of adult support, which further highlighted the importance of *school-parent interactions* in the adult-related social environment where asthma adherence is concerned in early adolescence.

Finally, adults' perspectives on the peer-related social environment were

explored. From their perspectives, the peer environment influenced asthma management not only via peers' immediate support towards asthma management, but also via peer activities within which *peer attention* to and *peer distraction* from young adolescents' asthma management behaviours intervened with adolescent behaviour. Theoretical connections between peer attention and social anxiety and between peer distraction and information exposure were briefly reviewed and hypothesised, but further studies are still required to confirm these hypotheses.

#### *Validity and relevance of the study*

In this study, the perspectives of school staff and parents were presented and compared. School staff observed individual differences within a group of students with asthma, while parents only observed their own young adolescents, but to a greater depth than school staff. Compared to the family environment, the school environment also represents a significant part of adolescent life, but the current asthma literature related to the school environment is surprisingly sparse. Therefore, the combination of perspectives in this study helped to validate the findings by describing the consistency and variety of the results from different perspectives. However, given the information described in the first part of the study that parents and school staff members had limitations in observing and recognising asthma management in early adolescent lives, not including the perspectives of young adolescents may result in perspective bias, especially when the peer-related social environment was explored. Therefore, in the next chapter, a different methodology was adopted to approach young adolescents' views of the peer-related social environment, which may be complementary to the findings of this study.

An obvious weakness of this study is not being able to generate causal or associative conclusions. However, this is an exploratory study that aims to describe the characteristics of the social environment within a specific context (i.e. asthma

management). Therefore, assessing internal validity with intentions to demonstrate quantitative associations is not always necessary. This is not to say that the study is free of weaknesses: Except for the theoretical and practical support from the supervisors of the researcher, the qualitative data were analysed by the researcher. Therefore, the results may be subject to the researcher's interpretation biases. However, the researcher was the only person that was experienced with the data, the interviews, and the contexts. Although discourse and agreement between different analysers may improve objectivity, it was not cost-effective in this minimally funded study.

Although the study included parents with different educational backgrounds, the participants were self-selected. Most children lived in two-parent families, and most parent interviewers were mothers. In addition, the study area was not representative for the UK, and the school environment in the UK might not be generalisable to other countries. These may all affect the validity of the study and the generalisability of the findings to a wider population.

Nevertheless, the study has presented some contextualised findings in the social environment of young adolescents' asthma management behaviour and has made attempts to connect the findings with the current literature in developmental psychology. The findings also highlighted the importance of contextual differences in psychological theories which may also provide useful information to improve the theoretical frameworks in future studies which focus on young adolescents' asthma management behaviour.

## **Chapter 6**

### **The social environment of asthma management: the perspectives of young adolescents (study 4)**



## 6.1 Introduction

Following the exploration of parents' and school staff members' views of asthma management in chapter 5, this chapter considers young adolescents' views, particularly their views of their peer environment related to asthma management. Compared to the adult interviews presented in chapter 5, a different interviewing methodology, a scenario-based interview, was adopted in this study to encourage young adolescents to share their feelings in their asthma management behaviour. By using scenario-based interviews, this study firstly explored young adolescents' views of the peer-related social environment in asthma management. This was then compared with adults' views (in chapter 5) to provide a more comprehensive picture on this topic. Secondly, the stress-coping activities adopted by young adolescents in reaction to the peer-related social stress were explored. As discussed in chapter 2, stress-coping is an important aspect of social competence. It is not only an activity to relieve stress, but how an individual reacts to stress is also a pattern of decision making. Meanwhile, the style of coping is context-dependent, and has been associated with medical adherence among adult populations (Peyrot et al., 1999; Stewart et al., 2003). Although there have been studies that establish stress-coping patterns and adolescent behaviour, stress-coping in the context of asthma management has not been studied in the literature. Therefore, the results of this study may contribute to our knowledge of adherence behaviour in addressing its relation to young adolescents' social life with peers. The result of this chapter has been published in *Journal of Asthma* (Yang et al., 2009).

## 6.2 Participants and Methods

This is a semi-structured interview study. The participants in this study were children of the parent participants in the adult interview study presented in chapter 5

(study 3). Young adolescents were interviewed using scenario-based (story-telling) interview protocols for twenty minutes to share their opinions on the characters' peer-related problems in asthma management in the scenarios. A summary of ethical considerations is attached in the appendix. In total, there were 34 young adolescents (aged 9-14), of whom fifteen were boys and nineteen were girls. Medication level and highest parent educational qualification are summarised in table 6-1. The median interview time was 16 minutes. Parents accompanied the young people in 11 of the interviews<sup>15</sup>.

TABLE 6-1 Summary of adolescent profiles

Variables	Number (%) Median (IQR)
Interview time (minutes)	16 (14, 19)
Parent accompanied	11 (32%)
Age	11 (10,12)
Gender (boy/girl)	15 (44%) /19 (56%)
Level of asthma medication	
No medication	1 (3%)
GINA step 1: Reliever only	11 (32%)
GINA step 2: Reliever and low dose preventer	16 (47%)
GINA step 3 and higher: Higher level of medication	6 (18%)
Parental highest educational qualification	
No qualification	2 (6%)
Post 16 qualification	6 (18%)
Post 18 qualification	6 (18%)
University	11 (32%)
Post-graduate	9 (26%)
<b>Total</b>	<b>34 (100%)</b>

\*IQR: interquartile range

### *Scenario-based interviews for young adolescents*

All young adolescents were interviewed in person (face-to-face). After a simple greeting, self-introduction, and brief explanation of the study, they were asked to read four scenarios (mini-stories) about peer-related problems in asthma management (see table 6-2 and appendix). The stories were written on story cards supplemented by

<sup>15</sup> Similar to the participants in other studies of this thesis, this adolescent sample has a higher socio-economic status (indicated by parental educational qualification) and more severe asthma compared to the county population where the sample was drawn.

coloured pictures, and were piloted on three participants aged 8, 10 and 14. The stories were generally well understood in the pilot study, but the interviewer was allowed to explain in the interview when it was not well understood (e.g. when they did not know what peak flow meter is). In each story, young adolescents were asked what the characters felt and what the young adolescents would do if they were the characters. After the four stories, three questions were asked to close the interview – whether or not it was more difficult to manage asthma in the school, whether or not friends talked about asthma, and whether or not people with asthma were less popular than people without asthma.

TABLE 6-2 Summary of child interview protocol

Topic	
Scenario 1	Feeling bad when not telling people of having asthma attack in a football match
Scenario 2	Feeling difficult to leave for getting the inhaler among new friends
Scenario 3	Skipping the peak flow meter schedules at school
Scenario 4	Feeling bad when there are older smokers in the party
Question 1	Is it more difficult to manage asthma in the school than at home?
Question 2	Do friends talk about asthma?
Question 3	Are children with asthma unpopular?

Scenario-based interviews have been compared to other methodologies of this thesis in chapter 2 (section 2.4). Specifically, although the scenarios are samples of peer-related experiences in asthma management, they might not be representative of all experiences in asthma management. Meanwhile, they were simulated contexts, not real contexts. Therefore, the results are limited by the selection of scenarios and the authenticity of the scenarios (compared to real life scenarios), and generalising the results could be dangerous. Nevertheless, this approach enabled young adolescents to engage in the interview conversations more effectively and comfortably: Young adolescents are sometimes less skilled and less motivated in expressing their feelings (Habermas and de Silveira, 2008), and the scenario approach provided an agenda to discuss, and kept the interviews focussed on the agenda so that the topics could be

discussed before the adolescents were tired or distracted (Caplan et al., 2005). Meanwhile, commenting on the scenarios was more interesting, and was less stressful than disclosing their own experiences. Therefore, this procedure is considered useful to allow young adolescents to engage in the interview more easily and comfortably (Diana, 2008; Westcott and Kynan, 2004; Wright et al., 2007).

The young adolescents were interviewed before their parents were interviewed (presented in chapter 5), so that their responses would be independent of parent responses. All participants were interviewed in their homes except one who chose to be interviewed in the University with her mother. Parents were recommended to be around in the house but not stay in the immediate vicinity of the young adolescents while they were being interviewed, although they were welcomed if they felt more comfortable staying with them. All young adolescents were interviewed in the school year of 2007/8 (between October 2007 and July 2008). £10 tokens were given to the adolescents and parents to reimburse the time they had spent (as approved by the research ethics committee). The interview time was acceptable to young adolescents, and none of them expressed unpleasant feelings during the interviews.

#### *Data management and analysis*

All interviews were transcribed by the interviewer. The data management was similar to the qualitative analysis in chapter 5. All transcripts were segmented into *dialogue units*, which were the shortest self-explanatory contexts, and usually consisted of several sentences. All dialogue units were numbered and listed in Microsoft Excel® with the exact sequence as in the transcript, supplemented by participant profiles and which topic (scenario or question) the dialogue units referring to. The dialogue units were then coded into open codes and themes, and the main analysis<sup>16</sup> and result presentation<sup>17</sup> followed a procedure similar to chapter 5.

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<sup>16</sup> All dialogue units were included in the analysis simultaneously. They were coded into open codes

However, because the interviews were guided with simulated scenarios, a preliminary analysis was conducted before the main analysis to provide an overview of each scenario so that the interview context could be described before the main analysis. The details of analysis are explained in each result section as indicated.

### 6.3 Results

#### Scenario overview

There were 1129 dialogue units in total. The percentages of dialogue units regarding each interview topic (scenarios and questions) were shown in table 6-3. Judging from the numbers of dialogue units, scenario 1 (30%) and 2 (29%) were discussed more than scenario 3 (9%) and 4 (15%).

TABLE 6-3 Summary of dialogue units

Topic		Number (%)
Scenario 1	Feeling bad when not telling people when having asthma attack in a football match	336 (30%)
Scenario 2	Feeling difficult to leave for getting the inhaler among new Friends	328 (29%)
Scenario 3	Skipping the peak flow meter schedules at school	103 (9%)
Scenario 4	Feeling bad when there are older smokers in the party	165 (15%)
Question 1	Is it more difficult to manage asthma in the school than at home?	47 (4%)
Question 2	Do friends talk about asthma?	74 (7%)
Question 3	Are children with asthma unpopular?	70 (6%)
Others		6 (1%)
Total		1129 (100%)

To provide an overview of each scenario, dialogue units of different scenarios were analysed separately. In each scenario, “should I...?” questions and “would they...?” questions were extracted from the data. “Should I...?” questions described

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that answered the research questions, and themes were generated from open codes with constant comparison and analytical induction. A target theme number was set between two to five if possible.<sup>17</sup> As in chapter 5, themes (or constructs) are presented and explained, and verbatim quotes are used and interpreted to clarify the themes. Quotes from the transcripts are *italicised*, followed by corresponding serial numbers of the dialogue units (for easy retrieval). In a quote, words in parentheses ( ) were spoken by the researcher, and words in brackets [ ] were memos that helped readers to understand the dialogues.

the options the characters had, and “would they...?” questions described the possible peer thoughts or reactions in the scenario. The results were presented with a narrative response for each scenario that completed the story with the characters’ unheard thoughts, as in screenplays:

*Scenario 1*

*Story*

*George is on a football team. He got an asthma attack during a game. In the beginning he felt just a little bit wheezy, but he didn’t tell the coach until he started to feel really breathless. They lost the game eventually. No one blamed him but he still felt very bad.*

Response

George was in a very difficult situation in the football match when he had an asthma attack. He could have told people that he had an asthma attack and called a break, but then he would have had to sit out from the game. He was also worried that he might play very badly and disappoint the team if he kept silent about the problem, but he was also worried that he might be accused of being lazy, or being a weak member of the team (table 6-4).

TABLE 6-4 Scenario 1 summary

<b>Scenario 1</b>	<b>Feeling bad when not telling people of having asthma attack in a football match</b>
Options	Should I... tell my friends that I have an asthma attack? tell adults that I have an asthma attack? take my inhaler? sit out from the game?
Peer actions and thoughts	Would they... be disappointed by me? accuse me of being lazy or weak?

## Scenario 2

### Story

*Cindy hasn't had asthma for a year. Yesterday the weather was really windy and she's got a little bit cough when she was having lunch break with some new friends. She did not take a puffer right away because she left the puffer in her locker. She didn't know how to explain to the new friends that she would like to go to get her puffer.*

### Response

Cindy was very worried. She was not sure whether or not she should let her new friends know that she "had a problem." But how could she go and get the inhaler? What if her friends did not understand or did not believe her? Would they feel bad about what she said? Would they tease her when they found out? (table 6-5)

TABLE 6-5 Scenario 2 summary

<b>Scenario 2    Feeling difficult to leave for getting the inhaler among new friends</b>	
Options	Should I... admit that I have asthma? explain what asthma is about? go and get my inhaler?
Peer actions and thoughts	Would they... understand what I say? believe what I say? be curious about what I do? feel bad about what I do? bully or tease me?

## Scenario 3

### Story

*Abi had bad days lately because her asthma got worse and she kept coughing during the night. She was asked to use peak flow meter four times a day on her*

*bad days, but she always skipped the one in the afternoon because she is at school.*

#### Response

Abi wondered whether she should use the peak flow meter. She might not be allowed to use it whenever she would like to. People might not understand what it was. They might feel curious and stare at her. Should she just explain to people? How? She might be bullied or teased. Maybe she could find a private place to use it (table 6-6).

TABLE 6-6 Scenario 3 summary

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**Scenario 3      Skipping the peak flow meter schedules at school**

options	Should I... use the peak flow meter? use the peak flow meter publicly? explain what the peak flow meter is about? ask for permission to use my peak flow meter?
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Peer actions and thoughts	Would they... stare at me or feel curious? understand what I do? bully or tease me?
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#### Scenario 4

##### *Story*

*Josh was invited to a party. There were always a couple of older kids smoking in the party. He had to leave very early when people started to smoke because smoke made him cough. He was afraid that nobody would invite him if he asked people not to smoke.*

#### Response

It is understandable that Josh would like to stay in the party even if there were people smoking, but what could he do? Could he ask people not to smoke? How to ask

people not to smoke without being rude? He might not be welcomed by these people or he might be bullied or teased by the older kids if he did not handle it well. Should he explain that he had asthma? If people have to smoke, was it possible to stay away from the smokers, or he must leave the party? If he left the party, would people understand his good will and not feel insulted? (table 6-7)

TABLE 6-7 Scenario 4 summary

<b>Scenario 4    Feeling bad when there are older smokers in the party</b>	
options	Should I... ask people not to smoke? explain that I have asthma? express my negative attitude on smoking? stay with the smokers, keep away from them, or leave the party?
Peer actions and thoughts	Would they... not invite me into their party? ask me to leave the party? understand me? take what I say as an insult? bully or tease me?

### **Peer-related social environment of asthma management**

Having described the overview of the simulated scenarios in this study, this study considered the concepts (or themes) extracted from the responses that described the activities and behaviour of peers or the relationships with peers that support or hinder young adolescents' asthma management, i.e. the peer-related social environment of asthma management. Among 1129 dialogue units, 490 (43%) dialogue units were coded with peer-related environment. Percentages of dialogue units describing each theme within all dialogue units are presented in table 6-8.

TABLE 6-8 Peer-related social environment, adolescents' perspectives

Theme 1	Peer attention	Peer evaluation	Peer affiliation
Description	Young adolescents avoid attracting peer attention by not emphasising individual differences	Young adolescents would like to impress their peers or not to disappoint their peers.	Young adolescents enjoy doing things with peers which may conflict with asthma management
Dialogue units (%)*	332 (68%)	145 (30%)	146 (30%)
<b>Examples</b>			
Scenario 1	Let people know that he has asthma	let the team down be accused of being lazy or being weak	(Not) be able to keep playing
Scenario 2	Tell friends that she has asthma Face peers' curiosity (Not) be understood	(Not) impress new friends be accused of making an excuse to leave be teased or bullied	(Not) be able to keep doing what they are doing
Scenario 3	Let people know that she has asthma Face peers' curiosity Be stared at (Not) be understood	be teased or bullied	Disturb people
Scenario 4	Let people know that he has asthma Say things different from others; be out-numbered Be isolated (Not) be understood	be accused of being rude be unwelcome	(Not) be able to enjoy the party

\*a dialogue unit can be coded into zero, one or more than one theme

To review the three themes that described the same topic from the adults' view of the peer-related social environment, *immediate support* describes the direct support in asthma management or facilitating asthma management; *peer attention* describes the situations where young adolescents tend to avoid being different in asthma management; *peer distraction* describes the peer activities which distract young adolescents from asthma management. By contrast, *peer attention*, *peer evaluation*, and *peer affiliation* were extracted from this study to describe young adolescents' view of the peer-related social environment. Therefore, these themes were not only compared with one another, but also compared with the three themes described in the adult interview study.

### *Peer attention*

As explained in the adult interview study (chapter 5, study 3), peer attention describes

the tendency for young adolescents to try to “blend in” with the peer environment, and not to attract peer attention or not to emphasise individual differences. However, the evidence seems to suggest that these thoughts may not always involve young adolescents’ anxiety about negative peer judgement.

Sometimes asthma regimes are difficult to adhere to because they make young adolescents feel they are different and cause social anxiety for being judged by peers in public:

*A 13 year-old girl with asthma*

*“(Is it more difficult to manage asthma in the school?) Uh yeah I suppose. Because some people might find it uncomfortable to do it at school whereas when you are at home, you can go and get it anytime, there are not really people watching. Only your parents really, but they are not really as curious as things like that. People aren’t going to judge you when you are at home. When you are at school, people might get different opinions about who you are when you take a puff. Think about different things than when you are at home. (but you are all right with it, just sometimes annoying.) yeah. (they don’t actually come up to you) no.” (#22980)*

However, there are situations where young adolescents do not necessarily consider other people’s judgement, and it is being under peer attention *per se* that is stressful. Therefore, peer attention with good intention can still be un-welcome:

*A 12 year-old boy with asthma*

*“I don’t [ain’t] being not popular but not unpopular because of my asthma. I think they kind of pity me having asthma. (is that necessary?) no I don’t really want them to. But they sometimes do, like I cough and they like ‘oh are you okay Niall’ “(#22120)*

Asthma management may make young adolescents feel uncomfortable by highlighting their differences, but what is as uncomfortable is young adolescents' emphasis of their own individual difference among peers, or (colloquially) "making fuss about small things." For example, in scenario 2, the girl Cindy felt it was difficult to explain to the new friends that she had an asthma attack and she needed to leave to get her inhaler. The stress of peer attention can be associated with over-disclosing (or over-emphasising) personal problems to the new friends:

*A 13 year old girl with asthma*

*"(is it different between good friends and new friends?) yeah. (why?) because with new friends, you don't know them as well, so that you might not want sort of put them off being your friend by telling them you have a problem." (#23100)*

Therefore, peer attention seems to be not simply about a fear of peer judgment. The perception or feeling different, and the perceived (or expected) peer judgment about emphasising personal differences may also contribute to the influence of peer attention on asthma management behaviour.

*Peer evaluation*

Although the previous theme "peer attention" seems to involve a great deal of peer judgement, it describes the tendency of young adolescents to avoid peer attention in order to avoid peer judgement. By contrast, *peer evaluation* describes a tendency for adolescents to wish to impress their peers or not to disappoint their peers. Sometimes asthma or asthma management is perceived as a negative characteristic among peers, while in many other situations it is not a negative characteristic, but it is contradictory to young adolescents' wish to impress their peers.

A dilemma was found in scenario 1, where a boy (George) did not want to tell people that he had an asthma attack, but still felt bad when they lost the football game because of his incompetence in sports.

*A: 11 year old girl, scenario 1*

*“He could have scored a goal if he hadn’t felt breathless. I guess it was not his fault but he still felt like that, no matter what happens. (Do you think it is guilty?) Could be guilty.” (#20290)*

*B: 12 year old boy, scenario 1*

*“Because he thought it was like is his fault, because I’ll feel like that sometimes. I mean it is not, you know, my asthma attack, it is when I still away, they seems to do much better without me.” (#21830)*

Young adolescents feel stressed when they are under-valued by their peers. In scenario 1, if they choose not to tell that they have an asthma attack, they might feel under-valued by peers for not playing as well as they should. If they choose to tell and take a break, they might find themselves under-valued as a weak one among peers.

Meanwhile, many young adolescents perceived having asthma itself as a negative characteristic, as a 10 year old girl shared her feeling in response to scenario 2, where a girl (Cindy) felt it difficult to explain to new friends that she had an asthma attack and needed to leave and get her inhaler:

*“I probably wouldn’t want to make big fuss on it or I wouldn’t want like people to think differently of me like... if you during sport, you won’t want them to say down for you or something like that. Or you can just think of asthma. ... (if you want to go to the toilet you wouldn’t mind to say) yeah” (#24570)*

The girl did not want to say that she had asthma, because she thought it might be a “negative feature,” especially in sports. Therefore, it was more difficult to adhere to asthma regimes when this was perceived to create negative impressions among peers.

Across the four scenarios, young adolescents also felt that there were possibilities in some peer environments to be teased, to be bullied, or to be misunderstood for being rude when they disclose that they have asthma. Therefore, young adolescents could find it stressful to manage their asthma when their management behaviour may make them negatively valued among peers.

### *Peer affiliation*

Peer affiliation describes the tendency of young adolescents to enjoy many things only with peers. Sometimes their asthma management makes them stop having fun with their peers, which makes it difficult for them to adhere to asthma regimes. Instead of considering peer attention and peer evaluation, they do not necessarily consider what other people think or how other people react. They simply choose not to manage asthma because they do not want to miss the opportunity to stay with friends. Therefore, it is very similar to *peer distraction* from asthma management in the adult interview (chapter 5, study 3), whilst the difference is that young adolescents did not always consider non-adherence as a result of peer distraction, but an intentional decision:

*A: 10 year old boy, scenario 1*

*“Most of the time I would tell coach that, um, go out for a little bit. But maybe like one in ten times only I feel that, I really like it is a good game or something, I am playing well and, I will wait for a bit. So I can’t actually be blaming him. (because you want to keep up. You don’t want to stop) Yeah.” (#20830)*

*B: 11 year old boy, scenario 2*

*“I think she is worried about leaving her friends because they might go after she leaves like two minutes and not waiting for her. So I think she sort of try to stay there with them and not go get the inhaler.”(#31060)*

Meanwhile, some young adolescents in this study found it more difficult to manage asthma or they tended to forget it when were busy in school. It was not because the school made a tight schedule for students, but because their lives were filled with activities with peers:

*“(do you think so?) yeah because like, people like you have to do it at certain times, and then sometimes you forget because it is a long day in the school, and you’ll be like oh I forgot to take my inhaler, and then in the lesson people might not let you yell out in the lesson. But when you are at home, your mom can remind you. They can decide and say, oh you can take your inhaler.”  
(#30870)*

#### *Summary of results and discussion*

Among the three themes extracted from young adolescents’ responses to four peer-related asthma management scenarios, *peer attention* describes young adolescents’ tendency to avoid being different or to avoid emphasising their difference from peers. By contrast, *peer evaluation* describes young adolescents’ wishes to impress their friends even when this conflicts with asthma management. Finally, *peer affiliation* describes young adolescents’ wishes to enjoy social lives with their peers, and sometimes this also conflicts with asthma management.

Compared to the themes in the adult interview study, one might argue that it was the “perceived” social environment investigated in this study (Nigg et al., 2008).

However, such an argument should be made cautiously. In quantitative studies, the perceived social environment is sometimes indistinguishable from perceived social support or social norms, which are usually measured with expressed or perceived social evaluation (de Bruijn et al., 2007; Motl et al., 2007). However, as discussed in chapter 2, this contradicts the core concept of social environment, which involves not only explicit social support, but also implicit life experiences that “unconsciously” influence human behaviour (Sandvik et al., 2005; Chen et al., 2007a). Using a scenario approach, the current study avoided asking interview questions directed *towards* the research question, but emphasised life experiences *around* the research question. The peer-related social environment does not necessarily reflect peers’ attitude towards asthma management, nor is it necessarily attributed by young adolescents as a causal factor of asthma management. Therefore, results in this study may still contribute to our knowledge of both actual and perceived peer-related social environment.

In explaining peer attention in the adult interview study, the role of social evaluation was emphasised. However, the results of this study suggest that social anxiety might be over-simplified if it is solely attributed on awareness of social evaluation -- peer groups are important source of identity for adolescents (Stone et al., 2008; Levy-Tossman et al., 2007). Sometimes young adolescents only want to “fit in” the peer group, and social anxiety can be generated when their self-concept is different from their peer identity (Brown et al., 2008). Some young adolescents may change their behaviour to fit peer identity and to reduce this anxiety (McElhaney et al., 2008a). Therefore, although peer attention and peer evaluation may be highly related, they do not always co-exist or co-explain the social anxiety. Another interesting distinction between peer attention and peer evaluation is the way young adolescents cope with the stresses they encounter in the social environment -- peer attention seems to be something “to avoid,” while peer evaluation seems to be something “to work for.” Although it is not possible to demonstrate a quantitative

association between the types of coping and the types of peer stress in this qualitative study, a closer picture of young adolescents' stress-coping activities in the peer environment was explored in this study, and it is presented in the next section.

In general, there are more similarities than differences in the themes that describe the peer-related social environment from adults' and adolescents' perspectives. Apart from the influence of peer attention and peer evaluation, peer distraction (adult interview) and peer affiliation (adolescent interview) both describe the peer environment in which young adolescents are diverted away from asthma management without deliberate thoughts. Although immediate support (as a theme in the adult interview study) is not seen in this study, this difference is possibly related to the interview design which guided adolescents towards social problems. Therefore, despite some perspective differences, this study confirms the results of the peer-related environment presented in chapter 5. Nevertheless, the validity of these peer environment concepts in relation to adolescents' asthma management still requires further study to assess.

### **Peer stress-related coping activity in asthma management**

In the adult interview study (chapter 5) and the adolescent interview study (this chapter) which both describe the impact of the peer environment, great emphasis was laid on young adolescents' perceptions, interpretations and reactions towards peer-related social stress or social anxiety. In this section, therefore, young adolescents' peer-stress-related coping activities adopted in the four scenarios were explored. A mixed-deductive and inductive thematic analysis (as described in chapter 5) was adopted to analyse young adolescents' responses to the scenarios. Peer stress-related coping activities are behaviour or activities adopted by young adolescents to overcome peer-related stress when they manage asthma. Therefore, an obvious way of coping by not managing asthma at all was not included. Strategies that helped

adolescents to cope with non-peer-related stress were also excluded. However, the study did not make any assumptions as to good or bad strategies. Therefore, the coping activities are described without discussing which was more beneficial for asthma adherence.

Guided by the same rules of qualitative analysis as in chapter 5, the themes describe the commonality of all coping activities belonging to the same category, and the uniqueness that distinguished the themes from others. Therefore, these coping activities were related concepts, not mutually exclusive options. Meanwhile, although some strategies were seen to reduce certain types of peer-related stress, there was no evidence to suggest a corresponding relationship between peer-related stressors and coping strategies. As a result, four coping strategies were extracted from the responses to four scenarios. They are “cognitive justifying,” “explaining,” “outsourcing,” and “un-disclosing” (table 6-9).

TABLE 6-9 Peer stress-related coping activity in asthma management

<b>Coping activity</b>	<b>Definition</b>
Cognitive justifying	justify the asthma management behaviour to themselves regardless of a non-supportive peer-related environment.
Explaining	explain to peers why they need to do the asthma management behaviours.
Outsourcing	seeking social support that can buffer or influence non-supportive peer-related environment
Non-disclosing	keeping the behaviour private

### *Cognitive justifying*

Cognitive justifying describes the way that young adolescents justify the asthma management behaviour to themselves regardless of a non-supportive peer-related environment.

*A: 10 year old boy, scenario 4*

*“if they, like, say, if they wouldn’t invite me to the next party its like why would*

*he want to go to that party, eh like, they are not like, they don't really care about him.” (#20230)*

*B: 11 year old girl: scenario 1*

*“I don't think they would blame him anyway because it's not his fault. It's just the medical problem.”(#28960)*

In example A, the boy had to leave the party because people were smoking, and he was worried that he would never be invited again. It was a peer affiliation-related stress, and what he did was cognitively justified by himself so that he still chose to leave the party regardless of the stress. In example B, the child was worried that he would be blamed for having an asthma attack and not playing well in a football match. It was a peer evaluation-related stress, and his behaviour was also justified -- “it is not his fault,” so that he could make his decision without regarding peer evaluation.

### *Explaining*

The theme “explaining” describes the fact that young adolescents need to explain to peers why they need to do the asthma management behaviours. Compared to cognitive justification, explanation is a coping activity visible to peers. It is assumed that the behaviour is more acceptable if the reasons are well explained and well understood by peers.

*A: 9 year old girl, scenario 2*

*“I would probably let the friends know that I had asthma, then I'd say I got a bit [of a] cough, can I go and get my inhaler from my locker. If they are nice friends they'll say yeah.”(#27300)*

*B: 11 year old girl, scenario 4*

*“well you probably if they really wanted to (smoke), I’ll say can you like go outside or somewhere because that make me cough or something. If they were your friends, they would stop.”(#25100)*

In example A, the girl was hesitating about whether or not she should explain to her new friends that she needed to leave the group and to get her inhaler. She felt that it would be more acceptable to the peers if it was explained clearly. This was a peer attention-related stress. Explaining to friends and making friends understand that the behaviour was “normal,” meant that peer attention could be reduced. Similarly, in example B the adolescent did not simply ask people not to smoke, but she asked them to do this favour for her because she coughs. The request could be considered more acceptable when understandable reasons were explained.

### *Outsourcing*

“Outsourcing” describes the fact that young adolescents seek social support that can buffer or influence the non-supportive peer-related environment. Compared to simple explaining, outsourcing is more instrumental – young adolescents sometimes felt it more comfortable to share feelings with close friends, which could be an instrument for them to raise an issue in public more easily:

*A: 11 year old girl, scenario 4*

*“(what would you suggest him?) I’d probably suggest that you should probably tell your mom or something, or tell other people that you don’t really like people who are smoking there so. And maybe they would ask them not to do it. if they don’t then... (would you ask people?) no because they might be a bit harsh on you. So I just tell people. (what if your mom is not there?) you’d probably when there is an adult there, or a friend, like your best friend, just tell them.”*

(#24300-24310)

*B: 10 year old girl, scenario 1*

*“(what would you do if you were George) I’d tell someone (tell friends or teachers?) I’ll tell a friend and they probably will tell the teacher. (what would the teacher do when you tell them?) I don’t know.” (#26980)*

In both examples, young adolescents felt it uncomfortable to attract public focus on their own, and tried to seek close friends’ social support, perhaps to share the peer attention.

*Un-disclosing*

“Un-disclosing” describes the fact that young adolescents keep the behaviour private if it is not supported by peers. Compared to the other three coping activities (cognitive justifying, explaining, and outsourcing), un-disclosing avoids peer attention and peer evaluation more effectively, but sometimes it involves lying or not telling the truth, which might make adolescents uncomfortable:

*A: 14 year old girl, scenario 2*

*“yeah I kind of know how she feels. I guess it could get serious, but I yeah I think she should tell them she wants to go to the toilet and then go to get the locker [and the inhaler]. That’s what I do. Because you know it can get really serious where she could die, so she probably should take it just in case.”(#27670)*

*B: 11 year old girl, scenario 2*

*“(would you say I need to get a puffer or I need to go to the toilet?) She should say I need to get a puffer because if she said I want to go to the toilet, then she*

*would have been straightly lying to friends. (and it is not a good idea)  
No.”(#20360)*

Adolescent A did not want to take the risk of confronting asthma issues among peers, and felt it easier to tell a lie when she needed to get her inhaler. By contrast, child B chose to tell the truth because being honest to friends was very important to her.

### *Discussion of the results*

As discussed in chapter 2, coping activities are immensely variable in style. In the literature, people with *approaching coping styles*, such as decision making or seeking understanding, are more likely to adhere to medical regimes (Weaver et al., 2005; Peyrot et al., 1999). *Non-approaching (cognitive) coping styles*, on the other hand, are self-comforting, and are useful to relieve stress when one realises that his/her effort will not eventually pay off (Brown et al., 2008). To improve adherence, therefore, it seems more important to encourage and enable approaching coping strategies (Christensen et al., 1995). However, qualitative evidence in this study suggests that cognitive justifying may still help to overcome peer-related stress in asthma management. Although the results are not quantitatively validated, they suggest that non-approaching coping strategies may not always hinder medical adherence, and whether they are named avoidance coping or emotional coping, they should be carefully defined and classified.

Many coping interventions emphasise problem-solving skills (Audrain et al., 1999; Ambrosino et al., 2008). People are taught to solve problems step by step, from defining problems to listing options, and then to evaluating consequences. Although selecting a suitable coping strategy is important, it is not possible to solve the problem successfully without generating a variety of options to choose from. Some studies have suggested that the “option-generating skills” might be related to creativity or

creative thinking, which helps people to generate alternative options specific to a given context (Treffinger et al., 2007; Oaburn and Mumford, 2006). With or without creativity thinking as core social skills, these studies have highlighted the context-specificity of these options (Felder-Puig et al., 2004; Roder et al., 2003). In the current study, cognitive justifying, explaining, outsourcing and un-disclosing were the coping tactics young adolescents might adopt in asthma-related peer scenarios. To improve asthma adherence in early adolescence, knowing the options generated by young adolescents in a simulated context may help adults to understand the adolescent behaviour as a part of their social life, and thus to provide more efficient support in peer-related stress.

The concepts of coping skills (or social skills) have been tightly linked to social competence and pro-social behaviour in the adolescent literature. However, social competence and pro-social behaviour hold different assumptions in the function of coping skills. The concept of pro-social behaviour often assumes that children and adolescents should be warm and friendly in order to be accepted by the social environment (Alderfer et al., 2001; Meijer et al., 2000; Frey et al., 2005). By contrast, the concept of social competence emphasises the ability to select whichever social strategy is more likely to be accepted by the social environment (Warnes et al., 2005; Dirks et al., 2007). From the latter (social competence) point of view, the current research assumed that a person was “allowed” to use whichever strategies in coping activities -- outsourcing strategies can be manipulative and un-disclosing strategies can be deceptive, but they were the coping activities adopted *within the (simulated) context*. These results suggest the existence of strategies that are not necessarily “pro-social,” and therefore should be carefully treated in social skills interventions that promote asthma management.

Finally, although young adolescents are sensitive to peer attention and peer evaluation, privacy is a protected human right (UN, 1948), and when privacy is

intruded on, one should not be simply asked to “cope with it.” In the literature, children and adolescents’ privacy has usually been discussed as an issue of information confidentiality (Charles-Edwards, 2005), but research on the development of the sense of privacy is rare, especially privacy among peers. However, some family research indicates that the sense of privacy develops as early as 12 years old, in parallel with the development of the sense of autonomy (Milnitsky-Sapiro et al., 2006; Solomon et al., 2002; Hawk et al., 2008). Therefore, it could be considered to be part of young adolescents’ right to privacy to avoid peer evaluation and peer attention. As young adolescents are encouraged to cope with their social stress actively and effectively, it is important to emphasise a social environment where young adolescents’ right to privacy can be fully respected.

#### **6.4 Summary and Conclusions**

This chapter considers young adolescents’ views of the peer environment related to asthma management. A scenario-based interview strategy was adopted in this study to encourage young adolescents to share their feelings of asthma management. Firstly, *peer attention*, *peer evaluation* and *peer affiliation* were generated as themes that described the peer relationships that may support or hinder asthma management. This result is similar to the concept of *immediate support*, *peer attention* and *peer distraction* identified in the adult interview study (study 3, chapter 5). Compared to the adult interview study, a new theme of *peer evaluation* was used in this study to describe young adolescents’ intention to impress their friends, as distinct from *peer attention* which young adolescents try to avoid. Meanwhile, although peer attention and peer evaluation are frequently related, they do not necessary coexist. On the other hand, *immediate support* was not seen in this study, perhaps due to the limitation of this study to provide examples only in peer-related social problems. Compared to *peer distraction* (in the adult interview study), the concept of *peer affiliation* in this study includes peers’ wishes to enjoy their social lives with their friends, but the two

concepts both refer to the influence of the peer-related environment without perceived social stress.

Afterwards, the coping strategies young adolescents adopted to overcome the peer-related stresses they encountered in asthma management were explored from the qualitative responses to the scenarios. Among four types of coping activities, *cognitive justifying* refers to justifying to oneself regardless of other peoples' attitudes, which seems to suggest that non-approaching coping activities are also used to solve social problems. Interestingly, *un-disclosing*, or keeping their asthma management behaviour private, was also an option for young adolescents to avoid social problems related to asthma although it is sometimes not considered a pro-social behaviour. Some young adolescents also thought of *explaining* to friends and *out-sourcing* for social support in order to gain a wider peer support for asthma management. Young adolescents tended to use multiple strategies in each scenario, and there was no evidence to suggest corresponding relationships between the types of coping activities and the types of peer stress.

#### *Validity and relevance of the study*

The validity issues in this scenario-based interview as a simulated context have been addressed in section 6.2 -- the four scenarios may not be representative of all asthma management scenarios, and results from a scenario study may not be completely generalised to real social contexts. However, this method guided young adolescents to share their experiences more effectively, and encouraged young adolescents to express their feelings in a comfortable way, which may improve the internal validity of the study.

On the other hand, the external validity of the study is similar to chapter 5 – the study is limited by the small sample size and the self-selected-ness of the participants,

which attenuated the sample representativeness. Unlike quantitative correlation studies, however, this qualitative study aimed to answer exploratory (not confirmatory) questions, where data richness was more important than sample representativeness. The participants in this study consisted of various ages, genders, asthma severity levels and parental educational qualifications, which maximised the data richness at a relative small sample size. Meanwhile, the small sample size kept these semi-structured face-to-face interviews affordable, and generated a moderate amount of qualitative data that were manageable to analyse.

Unlike previous studies in the literature where mid- and late adolescent perspectives of asthma management were investigated, the current study concerns a younger age group (age 9-14), and focuses on the peer-related social environment in early adolescence (Penza-Clyve et al., 2004; Buston and Wood, 2000; Chen et al., 2007a). The findings question the literature that assumes social evaluation as the primary source of social anxiety, and also question the literature that classifies coping activities with approaching-avoiding behaviour, or pro-social/anti-social behaviour. Although the topic is asthma management, it will be useful to test the generalisability of the results to other aspects of young adolescent behaviour in future qualitative and quantitative studies.

# **Chapter 7**

## **Discussion and Conclusions**



Although there has been some evidence in the literature showing that young adolescents adhere to asthma regimes less successfully than younger children, this has only been shown among chronic medication behaviours. This thesis regards asthma adherence as a group of behaviours in multiple dimensions (acute exacerbation behaviour, chronic medication, trigger avoidance, etc.), and it has sought to make a contribution to the literature by observing the developmental changes among different aspects of asthma management in early adolescence. However, observing developmental changes was more of a starting point than the main purpose of this thesis. Beyond this, this thesis sought to explore some psychological factors that may explain the changes seen in asthma management behaviour in early adolescence. In chapter 2, current literature in behavioural psychology was reviewed. Although it is generally agreed that cognitive factors (attitudes, self-efficacy, etc.) are strong predictors of behaviour, this does not mean that environmental factors should be of less concern. In fact, modern behavioural psychologists have started to view behaviour as a manifestation of an interaction between environmental stimuli and cognitive appraisal, and the importance of the environment has been increasingly emphasised in health behaviour research, especially in physical activity and smoking. Therefore, this thesis followed these theories in behavioural psychology to develop hypotheses that might explain the decline of asthma adherence in early adolescence. Young adolescents' social interactions in their living environment, or their *social environment*, were selected as a focus of this thesis. As young people reach adolescence, their social interactions become much more diversified, not only because of the increasingly enriched social interactions in secondary schools, but also because of their growing ability to appraise social interactions from different perspectives. It is therefore hypothesised in this thesis that changes in their social environment in early adolescence might be related to their difficulties in managing asthma.

However, the concept of the social environment is a complex and multi-faceted

theoretical construct. Although many studies have shown the importance of *specific social support* towards particular behaviour, recent studies have increasingly emphasised the importance of social connectedness and relatedness, sometimes referred to as social relationships or *social capital*. More importantly, it seems that the impact of the social environment can be context-specific. For example, a supportive social environment for physical activity might not necessarily be supportive for asthma management, and a supportive social environment for young children might no longer be supportive for adolescents. Therefore, although some studies have identified characteristics of a supportive social environment in general adolescent contexts, this thesis aimed to investigate the role of some social environmental characteristics in the context of asthma management in early adolescence. It is hoped that these investigations could make some contribution to our understanding of adolescent asthma and adolescent behaviour.

In this thesis, four studies were conducted to explore the relationships between young adolescents' asthma management and some aspects of their social environment. It is important to be aware that these four studies were all designed to approach a common research purpose, and thus each study focuses on a part of the whole picture. It is hoped that a more comprehensive picture can be gained by synthesising the evidence from different studies. This is discussed later in this chapter.

This thesis started with the development of an asthma adherence questionnaire for young adolescents and initial validation of this questionnaire (study 1, chapter 3). Similar to the Family Asthma Management System Scale (FAMSS) developed by McQuaid et al., multiple aspects of asthma management behaviours were considered simultaneously in this asthma adherence instrument (McQuaid et al., 2005). However, unlike the FAMSS that focused primarily on *joint* parent-adolescent report of asthma management knowledge and behaviour, this questionnaire is a behaviour-only asthma adherence scale that combined parent and adolescent *independent* reports of

adherence behaviour. Although further validation is still required to improve this scale, the reliability and the factor structure were presented in this study, and it has potential for clinical and school use in surveys or in interventions. Meanwhile, in line with previous studies which showed that young adolescents felt it increasingly difficult to adhere to chronic medical regimes (Dashiff et al., 2009; McQuaid et al., 2003), this study found a negative association between age and other aspects of asthma management among a small sample of young adolescents using this newly developed questionnaire.

After the asthma adherence scale had been developed and had shown a negative association between age and asthma adherence, it was next hypothesised that poorer asthma adherence in early adolescence may be related to dynamic changes in the social environment in early adolescence. Therefore, the relationships between asthma adherence and some aspects of the social environment were investigated in study 2 (chapter 4). The social environmental factors included in this study were a) asthma-specific social support from parents or from peers, and b) indicators of peer interactions or peer relationships, including peer stress-coping activities, parent-reported peer acceptance, and self-reported peer acceptance. These peer relationship indicators also represented some aspects of *social competence among peers* (Klima and Repetti, 2008; Burt et al., 2008; Gestsdottir and Lerner, 2007). Although asthma-specific parent support and asthma-specific peer support were both important in explaining asthma adherence in early adolescence, it was the decline of asthma-specific peer support as adolescents grew older that explained poorer asthma management in older adolescents during this period. Interestingly, in an environment where asthma-specific peer support was relatively weak, parent-reported peer acceptance seemed to make a stronger contribution to asthma adherence. Previous literature on adolescent aggressive behaviour and alcohol consumption has suggested social competence as a *resilience factor* which helped adolescents resist negative influences in a less supportive peer environment (Epstein et al., 2007; Burt et al.,

2008). Considering peer acceptance as an aspect of social competence, this result seems to support this theory in the context of asthma management.

Having explored some associations between asthma adherence and the social environment, asthma management was re-examined in study 3 and 4 (chapter 5 and 6) through an exploration of its meanings to participants who were involved in the social environment of early adolescence. This re-examination aimed to identify the characteristics of social relationships that may influence adolescent asthma management. In study 3, thirty-three school staff interviews and 36 parent interviews were carried out, and the data were analysed qualitatively. Despite some differences in perspectives, school staff and parents both supported young adolescents' asthma management via *instruction/regulation*, *empowerment* and *school-parent interaction*. This result not only confirms the literature in diabetes in highlighting responsibility shift (or responsibility share) as a unique concept in adolescent chronic illness (Beveridge et al., 2005; Helgeson et al., 2008; Palmer et al., 2009), but also provides real-life examples that distinguish autonomy granting (autonomy support) from autonomy enabling (empowerment) in responsibility shift. Meanwhile, school staff and parents thought that peers may still hinder young adolescents' asthma management via *peer attention* and *peer distraction* even when manifest peer attitudes were supportive. This finding represents some adult perspectives of peer relationships that can be compared to the adolescent perspectives investigated in study 4.

Peer relationships were further investigated in study 4 by interviewing 33 young adolescents with asthma using scenario-based semi-structured interviews. Although the reliability of young adolescents' self-narratives has been a challenge in the medical literature, it is usually agreed that their opinions and feelings should not be left out. Therefore, a scenario-based semi-structured interview was designed to help young adolescents to share their feelings in a relatively easy and comfortable (less self-disclosing) way (Habermas and de Silveira, 2008; Caplan et al., 2005; Diana,

2008). In addition to the characteristics of peer relationships shown in adult views (study 3) which are primarily related to manifest or perceived peer attitudes towards asthma management, the wish to participate in peer activities, or *peer affiliation*, was identified by young adolescents as one way in which peers influenced their asthma management. Subsequent analysis also helped to describe adolescents' coping activities in asthma-related social stress. Because young adolescents' voices have been under-represented in the literature, it is hoped that this study provides information that will enrich our understanding of young adolescents' asthma management.

As mentioned earlier, each of the four studies deals one or more aspects of the main research purpose i.e. to investigate the relationship between asthma management and the social environment in early adolescence. To elaborate, the thesis aims to contribute to theories in behavioural psychology and developmental psychology, and seeks answers to several plausible or exploratory questions related to the main research purpose. Having briefly summarised the four studies, therefore, the evidence is further discussed in order to revisit the research questions.

### *Early adolescence and asthma adherence*

In keeping with the negative relationship between age and adherence to controller medications found in the literature (Osterberg and Blaschke, 2005; Buston and Wood, 2000; McQuaid et al., 2003), this thesis has shown a downward trend of other aspects of asthma adherence. Over and above the general trends of a summative adherence assessment, this thesis also aimed to investigate and describe variations within the general trends. However, methodological difficulties were encountered in simultaneous comparisons between all participant perspectives. Given that school staff members were not able to report asthma adherence for a specific young adolescent, asthma adherence of young adolescents was reported through questionnaires (study 1 and 2) by parents and young adolescents, but not by school

staff members. Through exploratory and confirmatory factor analysis, the results seemed to suggest a factor structure of asthma adherence (acute exacerbation management, trigger avoidance and physical activity) in line with *a priori* categories of asthma management based on biological mechanisms.

However, an alternative story was told via the qualitative studies. Because the semi-structured interviews were designed for adults, thematic structures of asthma management were investigated qualitatively between parents and school staff, but not in adolescents. Interestingly, the qualitative studies suggested a similar factor structure to quantitative results, but led to an alternative interpretation of the factor structure. Adult observation and recognition appeared to be an alternative underlying mechanism that also explained the factor structure of the knowledge of asthma management. In other words, to school staff and parents, they are categories of asthma management with different level of observation and recognition, not necessarily with different biological mechanisms as may perceived by health professionals. In this way, the qualitative study provides an alternative explanation to the results of the quantitative study.

Unlike measurement of adherence to a specific behaviour (e.g. smoking), asthma adherence involves a combination of behaviours, and is clearly a multi-dimensional construct. Despite the consistency between the quantitative factor structures and qualitative thematic structures, knowledge and understanding of asthma adherence and the activities or behaviour related to asthma adherence are context-dependent and perspective-dependent. In other words, asthma adherence is conceptualised and defined by those who are personally involved, i.e. not simply by health professionals. As discussed in chapter 5, although many interventions have been assessed with psychosocial outcome measures (e.g. quality of life), the current scientific paradigm has not succeeded in including this perspective-dependent concept in quantitative analyses (Cooper et al., 2008; Pronyk et al., 2008a). As we conclude that use of

medication or other aspects of asthma adherence decline in early adolescence, it is also important to be aware of various dimensions of asthma adherence that complicate this conclusion. Therefore, this thesis has not only shown that early adolescence is a difficult time for asthma management, but it has also approached the various dimensions of asthma adherence from a developmental perspective which takes adolescent social contexts into account.

### *Adult-related social environment and asthma adherence*

Chapter 2 introduced a multi-dimensional concept of the social environment, including direct influence via specific social support and indirect influence via social relationships (or social capital). To align with theories on the family environment, three constructs (parental involvement, parental warmth and parental autonomy support) were taken from the current literature of developmental psychology to describe family relationships in early adolescence. These are important concepts which have explained the impact of the family environment on adolescent aggressive behaviour or psychological adjustment.

Among these social environmental concepts in a family, the concept of asthma-specific parent support (as an aspect of specific social support) was studied first in this thesis. The importance of parental support for general adolescent behaviour has been extensively investigated in the literature (Ellis et al., 2007; Modi et al., 2008; Gerald et al., 2008). In the quantitative results (study 2), although asthma-specific parent support was not associated with age in early adolescence, it was the strongest independent associative factor of asthma adherence compared to peer support and peer acceptance. Therefore, one may tentatively conclude that similar to other contexts, the relationship between parental involvement and asthma management remains strong in early adolescence, and asthma adherence may be jeopardised in an environment where adolescents are less supported by parents.

To further investigate this tentative conclusion, the qualitative interviews (study 3) explored the nature of the adult-related social environment in early adolescence – three aspects of adult support were presented (*instruction/regulation, empowerment and school-parent interaction*). Although the study did not quantify how much the three themes were implemented by adults, it suggested that some differences exist between the family environment of general behaviour and the family environment of asthma management behaviour. In particular, through empowerment, adults supported young adolescents to develop *decision-making competence*, and thus helped in shifting responsibility to young adolescents. Therefore, although the literature has emphasised parental involvement, parental warmth and autonomy support (autonomy granting) in early adolescence (Suldo and Huebner, 2004; De Groof, 2008; Berg et al., 2007; Wiebe et al., 2005), it might also be important to emphasise a three-way balance between autonomy granting, responsibility shift, and development of decision-making competence (i.e. autonomy enabling or empowerment). For example, unlike other contexts where it is optimal to shift health responsibility to people when they develop decision-making competence (De Goede et al., 2009), study 3 showed that responsibility shift and autonomy development were a natural process in adolescence. Therefore, responsibilities may have shifted year by year in adolescence even when adolescents have not been empowered to make well-informed decisions. It is hoped that by introducing the three-way balance, an optimal pattern of family relationships can be identified and promoted by further studies.

However, the role of responsibility shift was not supported by the quantitative results of this thesis -- in study 2, although parent-adolescent dissonance (the tendency for parents to estimate higher scores than their young adolescents) was arguably correlated with older age and higher parent support at a marginal level of significance, the relationship between asthma adherence and parent-adolescent dissonance was not established. Even if there was a relationship, there would still be

no simple explanation regarding the theoretical interpretation of this parent-adolescent dissonance. Therefore, future research is needed which could examine the role of family empowering support and responsibility shift using a more sophisticated design. Having recognised the limitations, as we conclude that parent support is critical to asthma adherence in early adolescence, attention should also be paid to the balance between maximising current asthma management and developing asthma management competence.

Therefore, the results of this thesis are generally in line with the notion of a multidimensional family environment as suggested by theories in developmental psychology. This includes the importance of specific parent support and parent-adolescent relationships. However, in contrast to autonomy granting or responsibility shift proposed in the literature in developmental psychology, empowering support is introduced in this thesis from the literature in health psychology as a context-specific concept that enables adolescent autonomy competence in the family environment. This may add to our knowledge when family theories are generalised to the context of asthma management.

#### *Peer-related social environment and asthma adherence*

The influence of perceived peer attitudes on human behaviour has been extensively investigated in previous studies (Tercyak, 2006b; Chen et al., 2006; Verkooijen et al., 2007), but whether or how this influence become prominent in early adolescence remains less clear. In this thesis, the quantitative results indicated that peer support, measured by perceived peer attitudes, was a significant independent associative factor of asthma adherence in early adolescence. Moreover, although parent support seemed to have a stronger association with asthma adherence than peer support, the level of parent support remained unchanged during early adolescence, and the decline of asthma adherence in early adolescence was explained primarily by the decline of peer

support in young adolescence. Therefore, these results generally supports the co-existence of asthma-specific peer support and young adolescents' asthma management behaviour, and seems to provide new information by observing the decline of peer support towards asthma management in early adolescence, which may, in part, explain the decline of asthma management during this period.

Instead of using “attitude” or “support” as keywords, the qualitative interviews investigated the peer “environment” of asthma management via explorations of (a) the activities or behaviours of peers and (b) the relationships with peers that supported or hindered young adolescents' asthma management. In other words, the results aim to explain how peer relationships and peer activities operated in the young adolescent's everyday life. The themes of the peer environment were *immediate support, peer attention and peer distraction* in the adult interviews, and *peer evaluation, peer attention and peer affiliation* in the adolescent scenario interviews (table 7-1). Immediate support, peer attention and peer evaluation all reflect some aspects of perceived peer attitudes. Therefore, despite the slight differences in the themes of the two interview studies, this thesis supports the literature by demonstrating that perceived peer attitudes play a major part in adolescent health behaviour (Peters et al., 2009; Tercyak, 2006a).

TABLE 7-1 Peer-related social environment, adult and adolescent perspectives

<b>Adult perspective</b>	
<b>Immediate support</b>	Peers' explicit support in asthma management or facilitating asthma management
<b>Peer attention</b>	Children feel anxious under peer attention in a small group or a larger crowd, and sometimes try to avoid this attention
<b>Peer distraction</b>	Following peers rules without feeling stressed
<b>Adolescent perspective</b>	
<b>Peer attention</b>	Young adolescents avoid attracting peer attention by not emphasising individual differences
<b>Peer evaluation</b>	Young adolescents would like to impress their peers or not to disappoint their peers.
<b>Peer affiliation</b>	Young adolescents enjoy doing things with peers which may conflict with asthma management

However, there are still aspects of the peer environment other than peer attitudes, e.g. peer distraction and peer affiliation represent situations where adolescents forget to or choose not to manage asthma when their minds are preoccupied by peer activities. Through these mechanisms, asthma adherence was compromised when there was little consideration of peer attitudes. Although there seem to be several concepts in behavioural theories related to this non-attitudinal peer influence (discussed in chapter 5 and 6), they have not been investigated in adolescence behaviour. Therefore, as we conclude that poorer asthma management in early adolescence is associated with more negatively perceived peer attitudes, we should also be aware of the limitation of this conclusion from not considering this non-attitudinal aspect of the peer environment. It is hoped that this thesis can provide context-specific qualitative evidence for further studies to measure this non-attitudinal peer influence in a quantitative way.

Although there are differences in qualitative themes between adult (school staff and parent) interviews and adolescent interviews, this may be a perspective-dependent artefact. In particular, adults considered that young adolescents forgot to use the inhaler because they were distracted by peers, while young adolescents reported that their behaviour was driven by a desire for peer affiliation. In addition to study 1 where consistency of factor structures demonstrated in the parent- and adolescent- reported combined questionnaires, this consistency of qualitative themes is also an example that shows the consistency between adult and young adolescent perspectives on asthma management, and also shows the value (or validity) of taking different perspectives into account. In general, there were more consistencies than discrepancies between perspectives. Although the discrepancies can be interpreted as research biases, they can also be important perspective differences which enrich our knowledge of the social environment.

Therefore, the studies in this thesis have confirmed the literature by demonstrating

the importance of specific peer support (or peer attitudes towards specific behaviour) in adolescent behaviour, and provided new evidence that generalises this literature to the context of adolescent asthma management. The studies have also provided context-specific qualitative evidence for future studies to describe or measure the peer environment.

### *Peer social competence and asthma adherence*

Having discussed the importance of peer support in early adolescence and the possible mechanisms in peer relationships that influenced asthma management, social competence among peers was also considered as an alternative aspect of the peer environment that was not specific to asthma management. Social competence is defined in this thesis as the competence to gain social acceptance. It was hoped that social competence among peers can be a useful concept that describes peer relationships, so that its association with asthma adherence could increase our understanding of the impact of peer relationships on adolescent asthma management. Meanwhile, the previous literature has suggested social competence as a *resilience factor* which helps adolescents to resist negative influences in a less supportive peer environment (Epstein et al., 2007; Burt et al., 2008). In this thesis, it was also hoped that social competence among peers could be a resilience factor that could help adolescents to maintain asthma management behaviour while they were not supported by peers.

Peer social competence was approached in two ways in this thesis, through peer acceptance and coping activities. Peer acceptance is an evaluative aspect of social competence and describes the degree to which social skills operated successfully within a social environment (Dirks et al., 2007; Warnes et al., 2005). Coping activities, on the other hand, represented a behavioural aspect of social competence, investigated in this thesis as the behaviour or activities (or strategies) young

adolescents adopted to deal with stress (Peyrot et al., 1999; Stewart et al., 2003). Although coping strategies have been investigated extensively in the literature, they are considered to be context-dependent, and thus a purpose of this thesis is to recognise the coping strategies or patterns used by young adolescents in the specific context of asthma management in the peer environment.

As a result in study 2, although asthma adherence was related to negative peer attitudes towards asthma management, young adolescents were able to maintain better asthma adherence when they were more socially accepted by peers. There are at least two ways to interpret this result. Firstly, compared to asthma-specific peer support, peer acceptance represents a general acceptance of the person, not simply approval of the specific behaviour(s). Therefore, the results seem to suggest that there are different levels (general and specific) of peer approval or acceptance in relation to asthma management. In other words, asthma management is explained not only by peer acceptance of the specific behaviour, but also by general peer acceptance of the adolescent *as a person* i.e. social acceptance. This subtlety is also seen in the qualitative interviews with young adolescents (study 4) -- young adolescents were concerned not only about peers' direct evaluation of the adherence behaviour, but also about the indirect impact of their own behaviour on their social lives with peers. They may be reluctant to implement adherence behaviour if they might attract attention from peers (peer attention) or if they might not have as much chance as their friends in participating in some activities (peer affiliation), regardless of explicit supportive peer attitudes towards asthma management. Therefore, it is not sufficient for peers to show supportive attitudes towards asthma management behaviours *per se*. Young adolescents also wish for the social aspects of asthma management to be accepted in the peer environment in order for them to fully enjoy social life with peers without encountered by concerns with adherence.

Secondly, peer acceptance is regarded as one aspect of social relationships, and this

result seems to suggest that successful social relationships (or better social competence) among peers is a resilience factor of asthma adherence. According to this interpretation, the differential effects of peer acceptance and asthma-specific peer support may be an example of how social relationships and specific social support interact with each other in shaping adolescent adherence behaviour. In study 2, peer acceptance was not only an associative factor of asthma adherence, but also a factor that moderated the association between asthma-specific social support and asthma adherence (as indicated by interaction analysis). Following this result, it is possible that social relationships moderate the effect of context-specific social support and influence human behaviour context-dependently. Although there have been some studies investigating the effect of social relationship indicators on adolescent behaviour (Helgeson et al., 2009; Schwartz et al., 2005; Poulin and Dishion, 2008), studies investigating the moderating effects of social relationships are relatively under-represented in the literature (Epstein et al., 2007). Therefore, this associative study provides an example of this theoretical and analytical approach for future longitudinal studies to elaborate.

In investigating another aspect of social competence, coping activities were studied to describe the strategies young adolescents used to relieve social stress. Although the quantitative study did not identify consistent and reliable coping activity categories, qualitative interviews revealed four coping tactics (*cognitive justifying, explaining, outsourcing and un-disclosing*) used by young adolescents in managing their asthma under peer-related stress. These tactics included both cognitive and behavioural tactics, or both emotional and problem solving-oriented tactics. Interestingly, although coping skills and pro-social behaviour are both considered social skills which help to improve social competence and social acceptance, these coping tactics were not always within the range of pro-social behaviour, and neither were they always within the coping strategies in the literature for social acceptance or social competence (Alderfer et al., 2001; Frey et al., 2005). Meanwhile, in contrast to the coping

questionnaires used in this thesis and many other studies which usually focus on emotional regulation, three of the four coping tactics (explaining, outsourcing and un-disclosing) are problem-solving tactics (Pretzlik, 1997; Felder-Puig et al., 2004; Folkman et al., 1991). Therefore, although we can define stress-coping universally as the use of particular activities to relieve stress, it still refers to a differential range of activities within each specific context. This may result in the non-transferability of the quantitative coping scales across different research topics.

One might tentatively ask whether or not problem-solving coping predicts better medical adherence better than emotional coping. From the qualitative studies, it is likely that *true* social competence seems not only the competence to be accepted by peers (behavioural coping), but also the competence to process the social information in order to *feel* accepted by peers (cognitive or emotional coping). However, the association between self-reported peer acceptance and asthma adherence was not significant in study 2, leaving this statement unsupported. Meanwhile, the non-successful attempts in quantitative coping measurement left this research question unsolved, and therefore the exact roles of different coping tactics in young adolescents' asthma adherence still require further research to disclose.

#### *Validating a school asthma adherence questionnaire*

Instead of investigating the asthma adherence behaviour of young adolescents, most studies have investigated *family adherence* in early adolescence (McQuaid et al., 2005; Gavin et al., 1999). However, family is not the only source of social support in adolescence, and therefore this thesis regards young adolescents as individuals within the school environment and the family environment. A different adherence questionnaire was developed to assess young adolescents' adherence behaviour, but not family adherence behaviour. Although it is still reported by parents and young adolescents, they reported separately (but not jointly), and they reported on the

adherence behaviour of young adolescents, not the adherence behaviour of the family. These are important distinctions that allow peer environmental factors (e.g. peer support and social competence) to be used to explain asthma adherence in this thesis.

However, compromises were made in the development of the questionnaires. Considering all young adolescents with asthma in the school, only a minority of them require controller medication. To keep the factor structure consistent across all young adolescents, items of controller medication and clinical visits were not included in the questionnaire. Although the internal validity may be improved by not including items applicable for all populations of interest, the internal validity may also be jeopardised for not including items that are relevant to health care providers.

Although this thesis aimed to explore the relationships between the social environment and asthma adherence in early adolescence, it also included extended validation study of this adherence questionnaire. The measurement properties, correlations, and differences among items, as well as the factor structures and the internal consistencies, were presented in the initial validation study (chapter 3). Associations were established in the initial validation study and the further quantitative association study (chapter 4) between this asthma adherence scale and age, medication level, asthma-specific parent support, asthma-specific peer support and peer acceptance. These associations not only demonstrated the property of this construct, but also showed the possibilities of using this scale in future studies or interventions where asthma-specific social support and social competence are considered.

Furthermore, the adult qualitative interviews (chapter 5) revealed the comparative perspectives between parents and school staff. Compared to parents, school staff did not observe or recognise controller behaviour as a part of asthma management in early adolescence. Therefore, although the adherence scale, which does not include

controller medication and clinical visits, may not be fully compatible with the clinical views of health professionals, it is relatively easy and useful for school staff to assess relevant young adolescents' asthma management behaviour *within the school context*. Although school asthma care has attracted more attention than before, there has not been a questionnaire designed for schools to assess young adolescents' asthma adherence. This asthma adherence scale may be used in the future to assess school-based asthma adherence interventions.

There are further limitations of this questionnaire which should be discussed. The sample size (86 parent-adolescent dyads) and the sample representativeness used to validate the questionnaire may not be optimal; there was no applicable "objective" measure to demonstrate concurrent validity and predictive validity of the questionnaire; compared to individual behaviour, it may be more difficult to understand "adherence" as a summative concept. Nevertheless, this thesis demonstrated a validation process of this reliable and easy-to-use adherence questionnaire. It has potential for assessing asthma adherence especially in school environment of young adolescents.

#### *Final comments on validity, limitation, relevance and future research*

Having mentioned and recognised the validity issues and limitations, this thesis started by addressing three gaps in the literature regarding asthma adherence in early adolescence. The first gap was related to under-representation of non-medication adherence in the literature. Therefore, asthma adherence was constructed in this thesis as a multi-dimensional concept including both medical and non-medical behaviour. Quantitatively, a structured adherence questionnaire was developed; qualitatively, adults' knowledge and understanding of asthma management were explored. As a result, this thesis demonstrated a collective concept of asthma adherence with multiple behaviour and multiple participant perspectives. Although this approach is

strengthened by including *many* aspects, it may be inevitably biased by not including *all* aspects. Even if it was possible to include all of them, it would also be difficult to develop a perfect way to summarise all information into one easily interpretable concept of asthma adherence. Nevertheless, although this summative view of asthma adherence may be less straightforward to interpret, a summative assessment may be useful for daily school asthma care in early adolescence. It is therefore hoped that future studies can elaborate and refine this summative view of asthma adherence, and link it to the adolescent outcomes that are broader than asthma management behaviour, such as quality of life, in order to fill the gap between the literature of medical and non-medical asthma management.

The second gap in the literature was the limited use of developmental psychology to aid to our understanding of asthma adherence in early adolescence. Therefore, in addition to the existing social environmental theories in (adult) behavioural psychology, this thesis explored the context-dependent constructs of the social environment in early adolescence – not only the behaviour or activities of others, but also the relationships with others. On the one hand, the thesis provides evidence that supports generalisation of behavioural or developmental theories to the context of asthma management in early adolescence, including the importance of specific social support (or perceived social norms) in human behaviour and the importance of social competence as a resilience factor. On the other hand, there are also results suggesting context-specificity (or non-generalisability) of these theories, such as the differential concepts of empowerment, autonomy and responsibility in early adolescence, or the coping tactics young adolescents used in response to peer-related stress in asthma management. Therefore, having recognised the research limitations mentioned earlier in this chapter, this thesis suggested that generalisation of social environmental theories into early adolescence may require further modifications informed by context-specific knowledge.

Finally, the third literature gap was the skewed information towards how asthma was managed *for* young adolescents, and the relatively small endeavour for how asthma was managed *by* young adolescents. Therefore, the thesis has focused on the behaviour of young adolescents as individuals, rather than the behaviour of families. With this perspective, it is important to include adolescents' self reports; thus self-reported questionnaires and scenario-based interviews were designed for young adolescents to share their feelings and opinions. More importantly, although it is clear that young adolescents are not fully independent, their dependence network extends beyond their parents. This approach allowed the thesis not to focus only on the family environment, but to recognise a major influence of the school environment in early adolescence. However, it is not possible to explore all aspects of the school environment, and it seems more studies are required to investigate the parent-school relationship. For example, it would be important to clarify the optimal ways of empowering support at home and at school when responsibility of asthma management is shifted to adolescents during primary-to-secondary school transition. Although it seems more questions are generated than they are answered, it is hoped that this thesis can be one example where research is focused (or re-focused) on adolescents as individuals in the social environment.

With a multi-method, multi-informant, mixed qualitative and quantitative design, this thesis aims to provide multiple views on the topic of interest. However, it is still not possible to exploit all of them. For example, the perspectives of peers and health care providers were not explored; the family study included mainly maternal perspectives, while the perspectives of fathers and siblings were absent. Furthermore, the multiple views were not all epistemologically or methodologically compatible. In fact, synthesis of evidence across different results was based primarily on the researcher's self-criticising, reasoning and knowledge of relevant literature. Therefore, the conclusions should be interpreted with the awareness of all these limitations.

Meanwhile, not being able to support a causal claim is a major weakness of this thesis. The qualitative studies (study 3 and 4) were not designed for making causal claims, and the quantitative studies (study 1 and 2) were association studies, which may be subject to spurious correlations or reverse causalities when causality is concerned. The sample size was not large, and was not perfectly representative for all young adolescents with asthma, which should also be considered when causal claims are made. Nevertheless, this thesis contributes to the literature by providing contextualised information, which may help future interventions in turn to confirm the hypotheses generated from this study.

In conclusion, this thesis has used different ways to address the relationship between asthma management of young adolescents and some aspects of their social environment. The inclusion of developmental approaches has provided new angles to describe the social environment of early adolescence, and this thesis has demonstrated quantitative and qualitative evidence to support this developmental angle. With recognition of research limitations, it is hoped that the results and the instruments developed in this study may serve as scientific resources for schools or health care providers. This implies not only to recognise the importance of young people's social life as much as asthma adherence, but also to understand more of the social behaviour of young people in the transition years to adolescence.

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## **APPENDIX**

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## 1. Asthma management behaviours

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Dimensions	Items
Drug adherence	1 Use inhaler when having an asthma attack
	2 Tell adults when not feeling well
	3 Keep inhaler at hand
	4 Use peak flow meter as planned
	5 Take preventive medicine on time
Trigger avoidance	6 Take care of self on cold/windy days (wear a scarf, take a puff of inhaler)
	7 Avoid air pollution or areas where people smoke
	8 Try to stay away from others who have a cold
Exercise management	9 Take part in physical activity when asthma is well controlled
	10 Warm up and down thoroughly during exercise

---

## 2. Schools

### 2.1 Invitation letter to the potential participating schools



University of Oxford

#### **PARTNERSHIP INVITATION**

Breathe In Speak Out Survey, Oxford ethics committee ref no. 06/Q1606/140

[date]

Dear Ms. [name],

I am a paediatrician and very concerned about children with asthma. Recent research evidence had shown that children aged 10-14 have more difficulties adhering to their asthma management regimes. I am therefore conducting a survey (Breathe In Speak Out) to help to understand this situation.

In this research, I am interviewing children with asthma (year 5-9) and their parents about their asthma management behaviours. As I am interested in children's interactions with their school friends at school, I am also inviting school teachers to join the interview survey and share experiences and opinions. I wonder if you could spare 30 minutes for me to talk with me in order for me to learn more about children with asthma at school. Your views are very important to me. Without them, the study will reflect the views only of children and parents, and may be biased.

We understand that school teachers are very busy, yet I hope you will be able to meet for a brief interview at a time and place to suit you. The interview topics are not particularly sensitive or controversial, but the interview data will still be kept anonymous and confidential.

By participating in the survey, you will receive a summary report of this research at the end of this survey (around September 2008). To teachers who might benefit from evidence of participation/collaboration (e.g. for job or further training application), a formal letter will be provided from Oxford University, Department of Education.

Please feel free to ask any questions. If you would like to join the interview,

please fill the informed consent form and send back to the research team. Or you may write an email to show your interest, which will save postal cost. Please contact:

[name, email, telephone number, address]

Best wishes,

[name] [signature]

## 2.2 Second invitation letter to the potential participating schools



University of Oxford

### **(SECOND) PARTNERSHIP INVITATION**

Breathe In Speak Out Survey, Oxford ethics committee ref no. 06/Q1606/140

[date]

Dear Parent(s),

I am a paediatrician and very concerned about children with asthma in the school. Recent research evidence had shown that children in year 5-9 have more difficulties adhering to their asthma management regimes. I am therefore conducting a survey (Breathe In Speak Out) to help to understand this situation.

\*\*\* This is our second invitation of this project. You might not have received our first invitation, or you were not able to help in our first invitation for practical reasons. In either case, I would be very grateful if you can consider (or re-consider) our invitation. You might think that you are not the best person to talk about asthma. I would then be as grateful if you can introduce our project to the right person in the school. Depending on the structure of the school, they are likely to be the head teacher(s), class teacher(s), teaching assistant(s), SENCo(s), matron(s), school nurse(s), health managers(s) or first-aider(s).

In this research, I am interviewing children with asthma (year 5-9) and their parents about their asthma management behaviours. As I am interested in children's interactions with their school friends at school, I am also inviting school adults to join the interview survey and share experiences and opinions. I wonder if you could spare 30 minutes for me to talk with me in order for me to learn more about children with asthma at school. Your views are very important to me. Without them, the study will reflect the views only of children and parents, and may be biased.

We understand that school teachers are very busy, yet I hope you will be able to meet for a brief interview at a time and place to suit you. The interview topics are not particularly sensitive or controversial, but the interview data will still be kept anonymous and confidential.

By participating in the survey, you will receive a summary report of this research at the end of this survey (around September 2008). To teachers who might benefit from evidence of participation/collaboration (e.g. for job or further training application), a formal letter will be provided from Oxford University, Department of Education.

Please feel free to ask any questions. If you would like to join the interview, please fill the informed consent form and send back to the research team. Or you may write an email to show your interest, which will save postal cost. Please contact:

[name, email, telephone number, address]

Best wishes,

[name] [signature]

## 2.3 School adult consent form

### **INFORMED CONSENT** (version 20070823) \*SCHOOL TEACHER INTERVIEW FORM

Study Title: "Breathe in, Speak out" –  
Psychological Aspects of Asthma Adherence in Late Childhood  
Research Ethics Committee Reference Number 06/Q1606/140

Contact: Dr. Owen Yang  
The Department of Educational Studies, University of Oxford  
15 Norham Gardens, OX2 6PY  
TEL: 07929 551876  
E mail: [owen.yang@green.ox.ac.uk](mailto:owen.yang@green.ox.ac.uk)

I confirm that I understand the information for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that data collected during the study may be looked at by the research team anonymously. The interviewer will be the only person who is able to identify me.

I agree to take part in the above study

\_\_\_\_\_  
School name

\_\_\_\_\_

Printed name

Date

\_\_\_\_\_

Signature

Your preferred time and place of interview

---

\_\_\_\_\_

(we will contact with you to arrange an interview)

Your e-mail: \_\_\_\_\_

Your phone number

\_\_\_\_\_

**Is there anything we should know before we contact you?**

Thank you for your help. Please send it back to us. You can use the freepost envelope we provide.

## **2.4 School adult interview protocol**

### **General Guide:**

Strictly adhere to the time table is not necessary

dress code: a little casual, name badge

expected time needed: 30-35 min

### **Preparation:**

the role of the interviewee in the school, profiles of the school (pupil numbers, gender, private), bus time table, recorder, interview pack (with protocol, asthma management behaviour list, and a sample of questionnaire), read again the thematic structure in the latest analysis from previous interviews.

### **A. Greetings and warming up (samples)**

Hi, I am Owen Yang from Oxford University. I come to have an interview with (names) for an asthma study.

Thank you for meeting me. I am from Breath In Speak Out Study. We are interested in children's asthma management in school. We had some interviews with school children and their parents, and we hope you can help talking about children with asthma in the school and give us some advice. So where are we doing the interview? I cannot remember everything here so I will record it (show recorder) and will write it down later. It is just for me. Is it alright?

How long have you been a teacher? How long have you been a SENCo? Is being SENCo a different experience?

### **B. Leading to the general focus on asthma**

Have you had experiences with children with asthma? Do you have any duty that involves taking care of children with asthma in particular? (records, procedures, policies)

What do other teachers usually do to take care of children with asthma in your school?

### **C. Leading to asthma management behaviour**

This is a list of ten asthma management behaviours that some children feel a little bit difficult doing it at school. In your opinion, do you think some of them are particular difficult at school?

\*Some behaviours might have been discussed in section B, it is good practice to show the behaviour list after there is nothing more for the interviewee to say, unless a substantial distraction from the topic is noticed.

\*Please discuss each asthma management behaviour if there is time. Please always be aware of the current thematic structure in the qualitative analysis.

#### **D. Approaching the same topic from a different direction**

As children grow older, do you think now you are worried about them even more or you think they are doing the job on his/her own pretty well on these behaviours?  
Do you think the strategy to treat children has to change when children become older?  
Do sometimes adults have to argue with children with asthma about their disease management?

We have heard some parents they think the schools being very involved but also some parents think the schools being ignorant. Do you think it is difficult to coordinate with parents or doctors to take care with children with asthma?

As far as you can tell, what kind of “special attention” is given to children with asthma in his/her school?

\*these questions can be incorporated into section B and C when it applies

#### **E. Cool down**

Is there anything more that you'd like to share with us about you asthma experience at school?

Thank you very much. This is really helpful. Are you aware of any children with asthma at year 5 to 9 in this school? These are anonymous questionnaires for children and parents (give a sample and take out the questionnaires). Would you mind to introduce to your students who have asthma?

These are all well prepared, let me show you.

When they open these there will be a cover letter for you to introduce the study. Then here are the parents and children questionnaires. These won't take them more than ten fifteen minutes. They can send it back anonymously with this freepost envelope. The cover letter explained everything.

As you know, the healthy school policy emphasizes child involvement, but it is not easy to encourage children to express themselves in a short period, so we provide some close questions in the questionnaires, using different ways to ask their experiences.

We will have an electronic copy of research results at the end. I guess it will be around September in 2008. Would you like me to send a copy to you?

### 3. General practice

#### 3.1 Invitation letters

##### GP information letters (version 20061209)

Dear Dr. \_\_\_\_\_

Breathe in, Speak out is a doctoral research project in the University of Oxford, focussing on the psychological aspects of asthma adherence in late childhood and carried out by Dr. Owen Yang, a paediatrician working on child behaviour issues in the Department of Educational Studies. The project involves a questionnaire survey targeting children aged 10-14 years, which is the age when asthma adherence begins to decline. We hope that the research will help health professionals to understand the mechanisms of asthmatic children's adherence, and provide evidence to inform medical practices.

We are asking your health centre to help by identifying eligible children and distributing an information letter to them. This would involve the following:

- (1) identifying a list of eligible children (and their parent's name), i.e. children aged 10-14 years with a diagnosis of asthma.
- (2) printing the address and sticking it onto the well-packed, pre-stamped envelope (a sample is provided with this cover letter)
- (3) Sending out the envelope.

This envelope will include an information letter and a cover letter from your clinic. A possible letter is provided with this sample.

Those parents who respond to the initial information letter will be considered for their eligibility, and those parents and children who are recruited as participants will be interviewed by Dr. Owen Yang using a structured questionnaire.

**Please be aware that the study will not need your health clinic to provide any access to the medical records, will not require a space or a room in your health clinic, and will not require interviews with any health professionals.**

The research is being reviewed by the medical ethics committee, and the participant recruitment procedure is estimated to be started in January, 2007. If you are willing to help, or have any inquiries about this project, please contact:

Owen Yang  
Dept of Educational Studies, University of Oxford  
15 Norham Gardens, Oxford  
OX2 6PY  
TEL: 01865 274785  
Mobile: 07929 551876  
E mail: owen.yang@green.ox.ac.uk

Thank you very much  
Best wishes,

## **4. Parent and child**

### **4.1 Cover letter to introduce the questionnaires**

#### **ASTHMA SURVEY INVITATION**

**Study title: Breathe In Speak Out –  
Psychological Aspects of Asthma Adherence in Late Childhood  
Oxford REC C reference number 06/Q1606/140**

Dear Parent(s),

I would like to introduce you and your child to an asthma questionnaire survey: “Breathe In, Speak Out (BISO).” It is a research project for adolescents with asthma to express their feelings about asthma control. We hope that they can control asthma and still enjoy their lives.

Joining the survey only requires you and your child to complete the attached questionnaires (10-15 minutes only) and send them back to the research team with the freepost envelope. If you have time, please also join the short interview by sending back the informed consent form with your questionnaires. You will receive a token (£ 10) if you agree to be interviewed. Please also indicate your choice in your informed consent form.

We are encouraging you to join the survey, but whether you join or not, your information will not be disclosed to the research group by the school or by the health centre. Please feel free to contact the research group if you have questions about the survey.

Best Wishes,

[school/GP staff, sector name]

## **4.2 Second cover letter to introduce the questionnaires**

### **ASTHMA SURVEY 2<sup>ND</sup> INVITATION**

**Study title: Breathe In Speak Out –  
Psychological Aspects of Asthma Adherence in Late Childhood  
Oxford REC C reference number 06/Q1606/140**

Dear Parent(s),

I would like to introduce you and your child to an asthma questionnaire survey: “Breathe In, Speak Out (BISO).” It is a research project for adolescents with asthma to express their feelings about asthma management. We hope that they can control asthma and still enjoy their lives.

\*\*\* This is the second invitation of this project. Because the survey is anonymous, we do not know whether or not you have participated before. If you had received this letter last time, we truly apologise for the inconvenience. If you had not received our first invitation, or if you were not able to help in our first invitation, I would be very grateful if you can consider (or re-consider) participating in this asthma project.

Joining the survey only requires you and your child to complete the attached questionnaires (10-15 minutes only) and send them back to the research team with the freepost envelope. If you have time, please also join the short interview by sending back the informed consent form with your questionnaires. You will receive a £ 10 token if you agree to be interviewed. Please also indicate your choice in your informed consent form.

We are encouraging you to join the survey, but whether you join or not, your information will not be disclosed to the research group by the school or by the health centre. Please feel free to contact the research group if you have questions about the survey. The contact can be found in the questionnaires.

### **4.3 Breathe-In-Speak-Out Questionnaire - parent version**

(start from the next page, slightly modified to suit the page size)



**Questionnaire  
for parents  
(V.200804)**



**What is the purpose of the study?**

When children with asthma reach adolescence, some of them find it easy to adhere to medical regimes on their own, while others do not. We hope adolescents can control their asthma and still enjoy their life. The purpose of this study is to listen to children and to find out why some children are more capable of maintaining their asthma adherence than others.



**Why have I (and my child) been invited to participate in this study?**

You have been invited to participate in this study because you are a parent of a child with asthma in year 5–9.



**What are we doing in this survey?**

You can participate in the study simply by completing the short questionnaire (15 min) and send back to us. If you have time, you can also participate in our short interview (30 min) after you complete the questionnaires. Please send back the consent form if you would like to be interviewed.



**Are there any possible risks or benefits to my child and I if I decide to participate?**

There is no obvious risk to you and your child. Parent and child who agree to be interviewed will receive a token (10 GBP) to compensate your time spent. The results will help other children and their parents to better control their asthma.

You and your child will be invited to a meeting with other participants at the end of the study. This would give you a chance to hear how other parents feel, perhaps giving you some useful ideas for your child.



**How would my privacy and anonymity be maintained?**

All your answers will be kept anonymous and confidential. The only individuals who would be allowed access to the data are the researcher (Owen Yang), his University supervisors and examiners.

Any publications about the project will contain no reference that could identify the parents or children. All data will be kept safely in a locked filing cabinet in a secure room, or on a password-protected computer. The raw data will be kept for up to 5 years, and will subsequently be destroyed.

This project has received ethics clearance through the NHS central office for the research ethics committee. (reference number 06/Q1606/140)

**Whom may I contact if I have any further questions?**



**Please Contact: Dr. Owen Yang**  
**Department of Education, University of Oxford**  
**15 Norham Gardens, Oxford, OX2 6PY United Kingdom**  
**E-mail: [owen.yang@green.ox.ac.uk](mailto:owen.yang@green.ox.ac.uk)**

**Section 1: My child's asthma symptom (tick the one that suits him/her best)**

**My child has asthma symptoms on**      \_\_\_ Less than 1 day a week  
   \_\_\_ 1 to 5 days a week  
   \_\_\_ 6 to 7 days a week

**My child has cough at night** \_\_\_\_\_      \_\_\_ Less than 2 days a month  
   \_\_\_ Less than 1 day a week but  
   more than 2 days a month  
   \_\_\_ More than 1 day a week

**How long has it been since asthma was diagnosed?**      \_\_\_ Year(s)

**How long has it been since the last time he/she had any asthma symptom?**      \_\_\_ Year(s) or \_\_\_ Month(s) or  
   \_\_\_ Day(s)

**Do you know the current severity of your child's asthma?**      \_\_\_ I am not sure  
   \_\_\_ Mild intermittent  
   \_\_\_ Mild persistent  
   \_\_\_ Moderate persistent  
   \_\_\_ Severe persistent

**What current medication is your child on?** Please write them below.

Drug name	Dose per day
Example: seretide	Example: 1 puff a day



**Section 2: Over the past six months, how often do you think your child did the following things? Choose the one that suits him/her best.**

Example: Over the past 6 months, my child \_\_\_\_\_ Always Usually **Sometimes** Occasionally Never brought his inhaler to school

If my child sometimes brought his/her inhaler to school in the past six months, I choose "sometimes"  
Now it's your turn

Over the past 6 months, my child \_\_\_\_ used his/her inhaler when he/she has an asthma attack Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ told adults when he/she is not feeling well Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ kept his/her inhaler at hand Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ used peak flow meter as planned Always Usually Sometimes Occasionally Never  
\_\_\_ tick here if he/she does not have peak flow meter

Over the past 6 months, my child \_\_\_\_ took his/her preventive medicine on time Always Usually Sometimes Occasionally Never

\*preventive medicine is inhaler or pills you need to take every day even if you do not have an asthma attack  
\_\_\_ tick here if he/she does not need preventive medicine

Over the past 6 months, my child \_\_\_\_ took care of him/herself on cold/windy days (wore a scarf, took a puff of inhaler) Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ avoided air pollution or areas where people smoke Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ stayed away from others who have a cold Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ took part in physical activities when his/her asthma was well controlled Always Usually Sometimes Occasionally Never

Over the past 6 months, my child \_\_\_\_ warmed up and down thoroughly during exercise Always Usually Sometimes Occasionally Never



### Section 3: Over the past six months, how often did you help or encourage your child to do the following things?

Example: (Over the past 6 months,) I \_\_\_\_\_ Always Usually Sometimes Occasionally **Never**  
helped/encouraged my child to bring his/her inhaler to school

If I occasionally encouraged my child to bring his/her inhaler to school in the past six months, I choose "occasionally."

Now it's your turn

I helped/encouraged my child to use his/her inhaler when he/she had an asthma attack Always Usually Sometimes Occasionally Never

I encouraged my child to tell adults when he/she was not feeling well Always Usually Sometimes Occasionally Never

I helped/encouraged my child to keep his/her inhaler at hand Always Usually Sometimes Occasionally Never

I helped/encouraged my child to use peak flow meter as planned Always Usually Sometimes Occasionally Never

\_\_\_ tick here if he/she does not have peak flow meter

I helped/encouraged my child to take his/her preventive medicine on time Always Usually Sometimes Occasionally Never

\*preventive medicine is inhaler or pills you need to take every day even if you do not have an asthma attack

\_\_\_ tick here if he/she does not need preventive medicine

I helped/encouraged my child to take care of him/herself on cold/windy days (wore a scarf, took a puff of inhaler) Always Usually Sometimes Occasionally Never

I helped/encouraged my child to avoid air pollution or areas where people smoke Always Usually Sometimes Occasionally Never

I helped/encouraged my child to stay away from others who have a cold Always Usually Sometimes Occasionally Never

I helped/encouraged my child to take part in physical activities when his/her asthma was well controlled Always Usually Sometimes Occasionally Never

I helped/encouraged my child to warm up and down thoroughly during exercise Always Usually Sometimes Occasionally Never



**Parent information (circle as relevant)**

**Your relation to child** Father    mother    others (specify \_\_\_\_\_)

**Father info** Father's age \_\_\_\_\_ father's job \_\_\_\_\_

Qualifications:

GCSE    A-level    University    Post-graduate

Other qualifications (if applicable) \_\_\_\_\_

**Mother info** Mother's age \_\_\_\_\_ Mother's job \_\_\_\_\_

Qualifications:

GCSE    A-level    University    Post-graduate

Other qualifications (if applicable) \_\_\_\_\_

**Child information**

**Age of child** \_\_\_\_\_ years old (In school year \_\_\_\_\_ )

**Gender of child** Boy    girl

**First language** English    others \_\_\_\_\_

**Family structure** Single-parent    two-parent    others \_\_\_\_\_

**THANK YOU VERY MUCH**

After the all the questions above, do you feel not able to say what you'd like to say about asthma?

Please join our 30 minutes interview with your child to express yourself.

It can be at any time and any place of your choice, and you will be reimbursed 10 GBP for your time spent.

Please discuss with your child. If you'd like to be interviewed, you can send the interview consent form back with the freepost envelope we provide.

#### 4.4 Breath-In-Speak-Out Questionnaire – child version



Questionnaire  
for children  
(V.200804)



#### What is the purpose of the project?

We hope children can control asthma and still enjoy their lives. The purpose of this project is to listen to children and to find out why some children find it difficult to control asthma.



#### Why have I (and my parents) been invited to participate in this study?

You have been invited to participate in this study because you are a child with asthma in year 5–9. At this age we start to make decisions on our own. Therefore it is important that you can join the survey with your parent(s).



#### What are we doing in this survey?

You can participate in the study simply by completing the short questionnaire (15 min) and send back to us. If you have time, you can also participate in our short interview (30 min) after you complete the questionnaires. Please send back the consent form if you would like to be interviewed.

If you agree to be interviewed, you will receive a token (10 GBP) for your time spent. You and your parent will be invited to a meeting with other participants at the end of the study. This would give you a chance to hear how other people feel about their children's asthma, perhaps giving you some useful ideas.



#### Would I be able to withdraw from the study at any time and for any reason?

Yes, you can withdraw at any stage without giving any reasons, and your health care will not be affected in any way.

This project has received ethics clearance through the NHS central office for the research ethics committee. It means your answers will be kept anonymous and confidential, and it is unlikely that you will suffer harm by taking part. If anything serious happens, then it will be reported to the appropriate authorities.

#### Whom may I contact if I have any further questions?



Please Contact: Dr. Owen Yang  
Department of Education, University of Oxford  
15 Norham Gardens, Oxford, OX2 6PY  
United Kingdom  
E-mail: [owen.yang@green.ox.ac.uk](mailto:owen.yang@green.ox.ac.uk)



## Section 1: Over the past six months, how often did the following happen? Choose the one that suits you best.

Example: I \_\_\_\_\_ brought my inhaler to school in the past six months

Always Usually **Sometimes** Occasionally Never

If I sometimes brought my inhaler to school in the past six months, I chose "sometimes"

Now it is your turn

I used my inhaler when I had an asthma attack

Always Usually Sometimes Occasionally Never

I told adults when I was not feeling well

Always Usually Sometimes Occasionally Never

I kept my inhaler at hand

Always Usually Sometimes Occasionally Never

I used peak flow meter as planned

Always Usually Sometimes Occasionally Never

\_\_\_ tick here if you do not have peak flow meter

I took my preventive medicine on time

Always Usually Sometimes Occasionally Never

\*preventive medicine is the inhaler or pills you need to take every day even if you do not have an asthma attack

\_\_\_ tick here if you do not need preventive medicine

I took care of myself on cold/windy days (wore a scarf, took a puff of inhaler)

Always Usually Sometimes Occasionally Never

I avoided air pollution or areas where people smoke

Always Usually Sometimes Occasionally Never

I stayed away from others who had a cold

Always Usually Sometimes Occasionally Never

I took part in physical activities when my asthma was well controlled

Always Usually Sometimes Occasionally Never

I warmed up and down thoroughly during exercise

Always Usually Sometimes Occasionally Never

**Well done!**



## Section 2: Do your friends think it is good that you do these things?

Example: Bringing my inhaler to school      My friends think it is    good    5    4    3    2    1    bad  
If they think it is very good, circle 5. If they think it is very bad, circle 1. 3 is the middle point (neither good nor bad). If I think my friends don't particularly feel good or bad about this, I circle 3.

Now it is your turn

Using my inhaler in an asthma attack      My friends think it is    good    5    4    3    2    1    bad

Telling adults when I am not feeling well      My friends think it is    good    5    4    3    2    1    bad

Keeping my inhaler at hand      My friends think it is    good    5    4    3    2    1    bad

Using peak flow meter as planned      My friends think it is    good    5    4    3    2    1    bad  
\_\_\_ tick here if you do not have a peak flow meter

Taking my preventive medicine on time      My friends think it is    good    5    4    3    2    1    bad  
\*preventive medicine is the inhaler or pills you need to take every day even if you do not have an asthma attack  
\_\_\_ tick here if you do not need preventive medicine

Taking care of myself on cold/windy days      My friends think it is    good    5    4    3    2    1    bad  
(wore a scarf, took a puff of inhaler)

Avoiding air pollution or areas where people smoke      My friends think it is    good    5    4    3    2    1    bad

Staying away from others who have a cold      My friends think it is    good    5    4    3    2    1    bad

Taking part in physical activities when my asthma is well controlled      My friends think it is    good    5    4    3    2    1    bad

Warming up and down thoroughly during exercise      My friends think it is    good    5    4    3    2    1    bad

**Section 3: Please recall and write down a recent bad experience you have had with ONE OR SOME OF YOUR FRIENDS.**



Example: *I argued with Jessie because she went to see a movie without telling me*

(write your experience here)

**Did that time make me feel... (tick ONE of them)**

	nervous or anxious		sad or unhappy		cross or angry
--	-----------------------	--	-------------------	--	----------------------

**At that time, what did you do about the situation?**

Example: I cried Quite a lot   **More or less**   None  
 If I cried a little bit at the time, I would circle "more or less"  
 Now it is your turn

1	I tried to forget it	Quite a lot	<b>More or less</b>	None
2	I did something like watch TV or play to forget it	Quite a lot	More or less	None
3	I stayed on my own	Quite a lot	More or less	None
4	I kept quiet about the problem	Quite a lot	More or less	None
5	I tried to see the good side of things	Quite a lot	More or less	None
6	I blamed myself for causing the problem	Quite a lot	More or less	None
7	I blamed someone else for causing the problem	Quite a lot	More or less	None

**Keep going! Only 2 pages left!**

**(Continue) At that time, what did you do about the situation?**

- |    |  |             |              |      |
|----|--|-------------|--------------|------|
| 8  | I tried to sort out the problems by thinking of answers                    | Quite a lot | More or less | None |
| 9  | I tried to sort it out by doing something or talking to someone about it   | Quite a lot | More or less | None |
| 10 | I shouted, screamed, or got angry  | Quite a lot | More or less | None |
| 11 | I tried to calm myself down  | Quite a lot | More or less | None |
| 12 | I wished the problem had never happened                                    | Quite a lot | More or less | None |
| 13 | I wished I could make things different                                     | Quite a lot | More or less | None |
| 14 | I tried to feel better by spending time with others like Family or friends | Quite a lot | More or less | None |
| 15 | I did nothing because the problem won't be sorted Anyway                   | Quite a lot | More or less | None |

**How do you feel about the way you have dealt with this situation?**



very good



good



okay



bad



very bad



## Section 4: Do you agree with the following statements about you?

Example: I like to play with friends

agree 5 4 3 2 1 disagree

If you agree with it very much, circle 5. If you disagree with it very much, circle 1. 3 is the middle point (neither agree nor disagree). If I agree with it a little, I circle 4.

I have a lot of friends

agree 5 4 3 2 1 disagree

I am popular with children

agree 5 4 3 2 1 disagree

I am likable

agree 5 4 3 2 1 disagree

I do things with other children (play, talk...)

agree 5 4 3 2 1 disagree

I find it easy to make friends

agree 5 4 3 2 1 disagree

I am important to classmates

agree 5 4 3 2 1 disagree

Most children like me

agree 5 4 3 2 1 disagree

### My asthma symptom (tick the one that suits you the best)

I usually have asthma symptoms on

Less than 1 day a week

1 to 5 days a week

6 to 7 days a week

I usually have cough at night \_\_\_\_

Less than 2 days a month

Less than 1 day a week but more than 2 days a month

More than 1 day a week

## THANK YOU VERY MUCH

After the all the questions above, do you feel not able to say what you'd like to say about asthma? Would you like to join our short interview to help other children with asthma? It can be at any time and any place of your choice, and you will receive 10 pound voucher for your time contributed. Please discuss with your parents. You can send back the interview consent form back (at the end of your parent's questionnaire).

## 4.5 Parent/child interview consent form

### INFORMED CONSENT (version 20080412)

Study Title: "Breathe in, Speak out" –  
Psychological Aspects of Asthma Adherence in Late Childhood  
Research Ethics Committee Reference Number 06/Q1606/140

#### PARENT PART

I confirm that I have read and understand the information sheet (version 200709M) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

I understand that data collected during the study may be looked at by the research team anonymously. The interviewer will be the only person who is able to identify me.

I agree to take part in the above study

\_\_\_\_\_

Printed name

Signature

Date

Your preferred time and place of interview

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

(we will contact with you to arrange an interview)

Your e-mail: \_\_\_\_\_

Your phone number

\_\_\_\_\_

**CHILDREN PART (to be completed by the child and their parent/guardian)**

I have read about this project and I understand what this project is about.

I have asked all the questions I want and have had my questions answered in a way I understand.

I understand it's OK to stop taking part at any time.

I am happy to take part.

If you do want to take part, please write your name and today's date

\_\_\_\_\_                      \_\_\_\_\_                      \*Your 10 pound token choice  
(interview only)  
Signature                      Date                      (circle one)    HMV            M&S  
Book token

Thank you for your help. Please send it back to us. You can use the freepost envelope we provide

## **4.6 Parent-child interview protocol**

### **General Guide:**

Strictly adhere to the time table is not necessary

dress code: a little casual, name badge

expected time needed: 20-30 min

Parents are suggested to be around in the house while the child is interviewed, but it is acceptable if the parents wish to be with the children to be interviewed. Children are welcomed in parent interviews, but if they are tired they can leave as they wish.

The interviewer is not allowed to be alone with the child.

### **Preparation:**

Please be aware of the information disclosed in the parent questionnaire. Please confirm the time, the location and the interviewee (parent only or parent with child) one to three days before the interview. Please make a note of the names of interviewees and the travel information. Please read again the thematic structure in the latest analysis from previous interviews.

### **Interviewer Safety**

Inform the safety contact person the time and place of the interview. Text the safety contact person after the interview is finished. The safety contact person should making contact with the interviewer if the text is not arrived on time.

### **A. Greetings and warming up (samples)**

Hi, I am Owen Yang from Oxford University. I come to have an interview with (names) for an asthma study. [making sure there are adults in the house before stepping in]

Thank you for meeting me. I am from Breath In Speak Out Study. We are interested in children's asthma management in school. We have had some interviews with school children and their parents, and we hope you can help talking about children with asthma in the school and give us some advice. So where are we doing the interview? I will need (child name) opinions on 4 stories about children with asthma (show cards). We will have a talk first and then I will ask the parent to join our discussion. So can I start with (child name)? It will take about 20 minutes. Is it all right?

### **B. Leading to child interviews**

Hi (child name), thank you for meeting me. It is going to be helpful because these are the situations happening to children with asthma. They need advice see what they can do in the situations. Then we will have some small questions (show pocket questions) if we got time. I cannot remember everything here so I will record it (show recorder) and will write it down later. It is just for me. Is it all right?

Here I have four stories where some children have troubles with their asthma in the school. You may have some suggestions for these people. Can you help me with the first story? [reading out the story loud]

### **C. Child scenario interviews (20-25 min)**

Please refer to the child scenario interview protocols

### **D. Leading to parent interviews (20-25min)**

(Parent), we are done here. Would you please join us?

(to the child) Was it okay? I found it helpful, thank you very much indeed.

How long has [name] been having asthma? How is it lately? (talking about the history of asthma and how the family and the child controls asthma)

This is a list of ten asthma management behaviours that some children feel a little bit difficult doing it at school. We have seen them in the questionnaires. In your opinion, do you think some of them are particular difficult at school?

\*Some behaviours might have been discussed in the general discussion. It is good practice to show the behaviour list after there is nothing more for the interviewee to say, unless a substantial distraction from the topic is noticed.

\*Please discuss each asthma management behaviour if there is time. Please always be aware of the current thematic structure in the qualitative analysis.

### **E. Cool down**

Has [child name] starts to take some responsibilities on asthma control? What does he do now, compared to years ago?

Are you happy with the school arrangement about children with asthma?

Is there anything more that you'd like to share with us about you asthma experience at school?

Thank you very much. This is really helpful. Great. I really thank you both for this.

This is going to be very helpful. Here is something I need to give you to thank you.

(give a balloon dog and token)

We will have an electronic copy of research results at the end. I guess it will be around September in 2008. Would you like me to send a copy to you?

#### **4.7 Child scenario interview protocol**

Scenarios can be read by the interviewer or the interviewee. Open discussion is encouraged in each scenario, followed by the supportive leading questions as appropriate. Scenarios are discussed one by one, followed by the three asthma questions in the end. Extensively exploring each scenario is not necessary, especially when it appears difficult to the interviewees (more likely to happen in scenario 3 and scenario 4, where some people may not have sufficient experiences)

##### **Scenario 1**



George is on a football team. He got an asthma attack during a game. In the beginning he felt just a little bit wheezy, but he didn't tell the coach until he started to feel really breathless. They lost the game eventually. No one blamed him but he still felt very bad.

Why did he feel bad? Would you feel bad?

What can you do in his situation? (pros and cons)

Sometimes children don't tell adults when they have asthma attack. Why?

Do you think that some children don't play sports because they have asthma? Why?

##### **Scenario 2**



Cindy hasn't had asthma for a year. Yesterday the weather was really windy and she's got a little bit cough when she was having lunch break with some new friends. She did not take a puffer right away because she left the puffer in her locker. She didn't know how to explain to the new friends that she would like to go to get her puffer.

Why didn't she explain to her friends and go to get a puffer?

What would you do if you were Cindy? But why didn't she just do what you said?  
Is it difficult to use inhaler in front of other people who do not understand? Do your friends understand?

Cindy left her inhaler in her locker. Is it difficult to have your inhaler at hand?

What else do you do to prevent yourself from catching a cold?

(for preventive medicine only)

Cindy's puffer is for emergency use, but you have some medicine to prevent asthma, right?

Do you think preventive medicine is useful?

Who helps you to take preventive medicine every day? How?



Abi had bad days lately because her asthma got worse and she kept coughing during the night. She was asked to use peak flow meter four times a day on her bad days, but she always skipped the one in the afternoon because she is at school.

She didn't explain why she couldn't use it at school. Do you have some ideas?

Many children bring inhaler but don't bring peak flow meter. Why?

Do you think peak flow meter is necessary?

Why did Abi always skip blowing peak flow meter at school?

Is it a little bit embarrassing using it in school? What would you do if you need to use it in school?

#### Scenario 4



Josh was invited to a party. There were always a couple of older kids smoking in the party. He had to leave very early when people started to smoke because smoke made him cough. He was afraid that nobody would invite him if he asked people not to smoke.

What is your suggestion to Josh? What should he do?

What didn't he do just what you said? What was he worried about?

Do you know anyone who smokes? What did you do when they smoke in front of you?

Do you also try to stay away from others who has got a flu in this way?

### **Asthma questions**

(asked by a school teacher Henry) Sometimes children feel more difficult to control their asthma in school than at home. Why?

(asked by a mother) Do friends talk about asthma? Have your friends talked to you about asthma?

(asked by a 6 year old child) Are children with asthma unpopular?

## **5. Ethical considerations**

The study was approved by the University of Oxford Central University Research Ethics Committee (CUREC), and the NHS Central Office of Research Ethics Committee (CUREC reference number 06/Q1606/140). It also followed the ethical guidelines of the British Psychological Society.

In participant recruitment, health professionals and school staff identified the eligible young adolescents from their database and sent out the information sheets without disclosing the personal details to the researcher. The researcher only acquired the personal contact information after the potential participants contacted the researcher on the phone, through e-mails, or by sending signed informed consent forms back to the researcher. Further information was available from the information sheet, including the researcher's phone number, office address and e-mail address. The researcher contacted potential participants to explain the interview after they had left their contact details and once they had agreed to participate, to arrange a time and place to carry out the interview. Signed parent and young adolescent informed consent forms were obtained before the interview. All participants were encouraged to consider for at least 24 hours before they decided to participate.

During the interview, the parent (or the caregiver) was present in the vicinity so that the young adolescent was not left with the interviewer alone. The interview questions and protocols were designed to avoid victim-blaming of the young adolescents or of the parents. When the young adolescents were interviewed, the parents were recommended to stay wherever he/she could see the young adolescents, but also were asked not to stay too close in order to avoid interfering with their frank answers. Young adolescents or parents who wished to stop or have a break during the interviews were fully respected. If necessary it was suggested that they might continue some other time if they agreed. There was no known risk to the participants, the researcher and other people. Apart from any immediate benefits that participants might experience as a result of expressing their views, they were likely to benefit from receiving research newsletters where research results were summarized in lay language. They might also feel positive about the contribution in helping others better understand children's thoughts and thereby improve their health. There was no adverse event observed in the interviews.

In terms of data management, all information gained from interviews and questionnaires was anonymous and confidential. It was not possible for anyone other than the researcher to identify the participants through the numeric ID. Names were stored in a locked cabinet and identification numbers were used in all electronic files. The only people who were able to see the information collected were the researcher and his supervisors or assessors. Any personal information was removed and destroyed before being analyzed. When any reports of the study are published, there will be no record of any names or other information that could help to identify the participants. The information that had been gathered was stored in a locked filing cabinet in a secure room. The information will be kept for up to 5 years, and then destroyed.