CHILDHOOD AND ADOLESCENT ASTHMA: A STUDY OF PERCEPTIONS, MANAGEMENT AND HEALTH-RELATED QUALITY OF LIFE MEASURES

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GLOSSARY OF ABBREVIATIONS AND ACRONYMS

95% CI	-	95% confidence interval
A & E	-	Accident and emergency department
ADHD	-	Attention Deficit Hyperactivity Disorder
ANOVA	-	Analysis of variance
AQoL	-	Active Quality of Living scale (CAQ-A, B and C Scale)
CAM	-	Complementary and alternative medicine
CAQ	-	Childhood Asthma Questionnaire
CAQ-B	-	Childhood Asthma Questionnaire (version B)
CAQ-C	-	Childhood Asthma Questionnaire (version C)
DIS	-	Distress Scale (CAQ-A, B and C Scale)
DPI	-	Dry powder inhalers
EFA	-	Exploratory Factor Analysis
FEA	-	Frequent episodic asthma
FEV1	-	Forced Expiratory Volume
FG	-	Focus groups
GPC	-	General Paediatric Clinic
HDB	-	Housing Development Board
HR-QoL	-	Health-related quality of life
ICC	-	Intraclass correlation coefficient
ICS	-	Inhaled corticosteroids
IFEA	-	Infrequent episodic asthma
KKH	-	KK Women and Children's Hospital
KMO	-	Kaiser-Meyer-Olkin test
LABA	-	Long acting beta agonists
MCID	-	Minimal Clinically Important Difference
MDI	-	Metered-dose inhaler
Mod-PA	-	Moderate persistent asthma
Mod-SPA	-	Moderate to severe persistent asthma
MOH	-	Ministry of Health
MPA	-	Mild persistent asthma
MRT	-	Mass Rapid Transit
NAEPP	-	National Asthma Education and Prevention Program
NASC	-	National Asthma Shared Care Programme
NHG	-	National Healthcare Group
PAQLQ	-	Paediatric Asthma Quality of Life Questionnaire
PCA	-	Principal Component Analysis
PE	-	Physical Education
PQoL	-	Passive Quality of Living scale (CAQ-A, Band C Scale)
QoL	-	Quality of Life
REACT	-	Reactivity Scale (CAQ-C Scale)

SABA	-	Short acting beta agonists
SD	-	Standard deviation
SEV	-	Severity Scale (CAQ-A, B and C Scale)
SNAP	-	Singapore National Asthma Programme
SPA	-	Severe persistent asthma
SPSS	-	Statistical Package for the Social Science
SRPC	-	Specialist Respiratory Clinic
TCM	-	Traditional Chinese Medicine
TQoL	-	Teenage Quality of Life Scale
UK	-	United Kingdom
VAS	-	Visual analogue scale
VCD	-	Video Compact Disc
WHO	-	World Health Organisation

EXECUTIVE SUMMARY

In Singapore and many developed countries, asthma is the most common chronic childhood disease, and exerts significant burden on the children and their caregivers' physical, emotional and social well-being. Despite the effectiveness of current pharmacological treatment, it continues to be the one of the main causes of visit to primary care doctors and utilisation of emergency care and hospitalisation. Therefore, a more holistic research approach that places the patient and family as the focus is needed to further understand what other steps are needed to improve the care of asthma.

Effective self-management is crucial factor in ensuring good health outcomes in asthma. The patients or their caregivers would need to possess sufficient knowledge of their conditions or treatment plan, and take the appropriate action. Secondly, they must be willing to adhere to the recommended treatment plans or course of action.

Patients with low health literary are disadvantaged in the first aspect, and need extra help through patient education. However, for this to be effective, the second aspect must to be addressed. Education programmes must not only be informative, but also address aspects existing health beliefs. Therefore, health care providers need to have a good understanding of patients' beliefs and management of asthma at home.

In this holistic approach, health-related quality of life measurements are important, as acts both to inform on areas which need attention, and also as a tool to evaluate the effectiveness of educational programs holistically.

With this background in mind, the thesis is organised around these objectives:

- First, we wanted to know much parents of asthmatic children know about asthma, and which are the groups that should be prioritised in patient education.
- Secondly, we wanted to understand how asthma is actually managed at home, and identify factors or beliefs which contribute or prevent appropriate management.
- Thirdly, we wanted to evaluate the public, or the society's perception of asthma.
- Lastly, we wanted to measure the impact of asthma in children's quality of life. Therefore, we examined the possibility of adapting an instrument developed in a Western country for patients in Singapore.

In line with these objectives, we made the following findings:

- Firstly, patients cared by non-specialists were often from lower socioeconomic groups. Their caregivers have poorer understanding of asthma, and the children had worse health outcomes. This group need to be targeted in asthma education.
- Secondly, asthma has significant impact on the whole family. Food is believed to cause symptoms (or even the disease), and also the cure. There are many misconceptions about asthma and steroid inhalers. Therefore, mothers must be educated, and also supported against the misinformation from others. The concerns and implication of having asthma differs from the Western studies.
- Thirdly, the public's understanding of asthma and medication is till relatively poor. Ethnicity is a factor which affected type of misconceptions harboured.
- Fourthly, the CAQs (Childhood Asthma Questionnaires) have good structure and easily understood by Singaporean children. However, more work is recommended to determine its validity in Singapore, which could have been affected by cultural differences.

PUBLICATIONS

Papers

1. Chong LY, Chay OM, Li SC. Is the Childhood Asthma Questionnaire a Good Measure of Health-related Quality of Life of Asthmatic Children in Asia? Validation of Childhood Asthma Questionnaire (CAQ-B) Among Asthma Paediatric Patients in Singapore. Pharmacoeconomics 2006; 24 (6): 609-621.
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Abstracts and Conference Proceedings

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4. Chong LY, Neo SB, Tan AL, Chay OM, Li SC. Parental Perception of Childhood Asthma and its Medication. [Abstract] KK Women and Children's Hospital 5th Paediatric Scientific Meeting. 19 – 21st September 2002, Singapore.
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6. Chong LY, Chay OM, Li SC. Correlation between Child-Reported Health Related Quality Of Life and (HRQL) with Parent and Physician Reported Severity. International Society for Pharmacoeconomics and Outcomes Research (ISPOR) First Asia Pacific Conference, 1-3 September 2003 in Kobe, Japan.
7. Chong LY, Li SC, Chay OM, Chua LL, Teo AH, Mohd Yatim Z. What are the Important Sources of Health Information for Singapore Residents? Proceedings of the 17th Singapore Pharmacy Congress 1-4 July 2005, Singapore.

Chapter 1. Introduction

1.1 CHILDHOOD ASTHMA AND MANAGEMENT

1.1.1 Overview of childhood asthma

Asthma is the most common chronic childhood illness in Singapore, affecting 1 in 5 children (Wang et al., 2004; Goh et al., 1996; Chew & Lee, 1998) and a significant burden (Lim et al., 2003). In children less than 15 years old, asthma is second to accidents and injuries as the principal illness for hospitalisation (Chew et al., 1998). It is also the second leading condition for visiting a general practitioner and primary health care clinic for this age group (Chew et al., 1998). Research on how this disease impacts on children's quality of life and whether the interventions and treatments provided is useful would contribute to the management of the disease.

1.2 ASTHMA MANAGEMENT-PARENTS THE IMPORTANT PARTNER

For children, parents are very important partners in the management of asthma. Once away from the source of care, the burden of care falls onto parents to ensure that the treatment plans are followed, or the recommendations given by the healthcare provider (if there are any) gets implemented. Parents, especially the mothers, also play the role as gate keepers and determine access to healthcare. They would identify the child's symptoms, and make decisions on whether a child is sick, needs treatment and what kind of treatment should be seek.

Whether they have the knowledge to carry out those roles effectively and whether they believe in doing it are two factors which are crucial to successful

management, and need to be addressed. Studies in the United States among Black and Navajo patients showed that the barriers to quality asthma care were more dependent on patients' beliefs and attitudes rather than access to care issues (Mansour et al., 2000; Van Sickle & Wright, 2001). The perception of asthma medications could affect their adherence and ultimately the children's asthma control and quality of life (Osman, 1997).

Studies also have shown that parents influence their children's' coping strategies, and quality of life. Their own attitudes towards a disease would, therefore, influence the child's.

1.2.1 Education as the key to improved management

Among other factors, asthma knowledge is amenable with appropriate education. Patient education had been given a lot of emphasis in asthma practice guidelines and the latest National Asthma Education and Prevention Programme (NAEPP) update identified education for partnership in care as one of the four recommended-as-essential components of asthma management (Global Initiative for Asthma., 2002; National Asthma Education Program expert panel report., 1997; National Asthma Education and Prevention Program., 2002).

1.2.2 Are parents equipped enough? How much do parents know?

Studies on parental or patient knowledge generally found the understanding about the disease or its management poor, and this could be a hindrance to effective patient-

provider partnership to manage asthma (Shivbalan et al., 2005; Conn et al., 2005; Belessis et al., 2004). Socioeconomic factors could influence the functional health literacy, and therefore the asthma knowledge, and patient education is generally advocated to bridge these gaps.

In Singapore, previous studies which surveyed the knowledge or inhaler technique of asthma patients generally showed that knowledge is lacking, and the patients could potentially benefit from patient education efforts (Lim et al., 1996; Tan, 1999; Wong et al., 1994).

Among these, the study conducted at a specialist respiratory clinic of a tertiary paediatric hospital specifically evaluated the impact of a one-to-one education intervention on asthma knowledge and outcomes. Asthma knowledge, metered dose inhaler (MDI) technique, self-reported compliance and symptom scores did improve significantly after the intervention (Tan, 1999). This highlighted that an educational intervention can still contribute to improve disease management (Alessandro et al., 1994) even in specialist clinics that were expected to provide better patient care for chronic diseases (Sperber et al., 1995; FitzGerald, 2001; Schatz et al., 2005; Vollmer et al., 1997; Kanter et al., 2002; Wu et al., 2001).

The level of asthma knowledge might be even lower in a non-specialist setting, as demonstrated by the findings of a 1992 study conducted in government polyclinics showing the elderly and the less educated had especially poor knowledge and MDI techniques (Wong et al., 1994). The parents might also have misconceptions

about inhalers which prevented them from complying with the treatment (Lim et al., 1996).

1.2.3 Could education help?

So far, the consensus is good knowledge itself does not directly translate to positive attitude and behavioural changes (Ho et al., 2003; Kolbe et al., 1996). Programs which merely serve to "transfer" information to patients did not seem to be effective (Gibson et al., 2002). Other intrapersonal factors such as feelings, health beliefs and attitude are also important (Clark & Starr-Schneidkraut, 1994). In turn, external factors and resources such as social support, and role models can affect these characteristics (Clark et al., 1994).

There were mixed results regarding the effectiveness of education as a tool to improve the outcomes of patients with asthma (Smith et al., 2005). These inconsistencies have been attributed to factors such as different content, purpose, target population and intensity of programmes. Some researchers even reported a difference of education impact between different ethnic groups (Mitchell et al., 1986; Moudgil et al., 2000). Some studies have pointed out that it generally improved the symptoms, but not necessary utilization of emergency medical facilities (Smith et al., 2005), while others concluded that when asthma education and self-management programs improves in terms of hospitalizations, emergency department attendance, symptoms or quality of life to various extents (Smith et al., 2005; Choy et al., 1999; Gibson et al., 2003; Chiang et

al., 2005). The effects had also been reported to differ between adults and children (Moudgil et al., 2000).

One area where asthma education had been shown to be beneficial was among patients with low functional health literacy (Paasche-Orlow et al., 2005). Low functional health literacy has been shown to be associated with poorer outcomes and management skills among patients with chronic diseases like asthma and diabetes (Williams et al., 1998b; Williams et al., 1998a; Schillinger et al., 2002). However, patients' asthma knowledge and self-management skills have been shown to be variables which could help the barriers cause by poor health literacy and had been associated with better outcomes and quality of life (Mancuso & Rincon, 2006).

1.2.4 Listening to the patients, parents and caregivers

Patients' and parents' knowledge about asthma have been shown to be generally lacking (Lal et al., 1995; Shivbalan et al., 2005; Zhao et al., 2002). Their perceptions of asthma may not concur with the asthma pathophysiology and treatment strategies proposed by health professionals. For example, asthma was still commonly thought to be infectious by some parents, particularly among studies conducted in the south Indian subcontinent, and food were identified as the main triggers in Asian countries (Hazir et al., 2002a; Lal et al., 1995; Shivbalan et al., 2005). Healthcare professionals need to have the cultural competencies and understand the patient's perspective of asthma and its treatment in order to address their concerns and explain the treatment approaches effectively and arrive in mutually agreed treatment plan which is an important part of concordance.

1.2.5 What is the public's perception of asthma in Singapore?

Due to high prevalence of childhood asthma in Singapore, members of the public have a high chance of having someone around them affected by asthma, be it an asthma patient or the parent of asthmatic children (Wang et al., 2004; Goh et al., 1996). Therefore it would be interesting to find out more about what the general public thinks about asthma.

1.3 WHAT IS QUALITY OF LIFE?

Another important issue is the impact of asthma on the quality of life, in particular health-related quality of life, of the patients. Quality of life is based on a multi-dimensional concept of well-being and health. It has been defined as 'physical, social and emotional aspects of a patient's well-being that are relevant and important to the individual' (Pharmacoeconomics, 2005). Health related quality of life (HR-QoL) has been defined as 'QoL measures that are likely to be influenced by health interventions' (Bender, 1996; Pharmacoeconomics, 2005) and HR-QoL has been described as an individual's "subjective perception of the impact of health status, including disease and treatment impact on physical, psychological and social functioning" (Leidy et al., 1999).

1.3.1 Why is it important to measure quality of life?

Health-related quality of life (HR-QoL) measures provide valuable information on the significance of an intervention from the patient's perspective (Testa & Simonson, 1996a). These are complementary to clinical severity or the conventional clinical and laboratory measures as improvements in these latter values do not guarantee that the

patient has benefited in daily life from the health interventions provided (Juniper et al., 1993; Juniper & Guyatt, 1996a; Juniper, 1999c; Marks et al., 1993; Nouwen, 1983c; Rowe & Oxman, 1993). This is especially true in chronic conditions such as asthma where patients experience exacerbations and remissions (Clark, 2003).

In paediatric patients, a good HR-QoL instrument also serves as a medium where young children can convey their experience of living with an illness instead of relying solely on reports from parents or caregivers. Common chronic childhood conditions like childhood asthma are areas where HR-QoL instruments that cater to their age or developmental stage could be utilised in this manner (Eiser et al., 2000; Wallander et al., 2001; Annett, 2001). However, HR-QoL measures are still rarely used in children in Asia partly due to the difficulty of obtaining valid, reliable instruments that are developmentally and culturally suitable, and partly due to the inexperience of the clinical community in using HR-QoL instruments (Bender, 1996; Connolly & Johnson, 1999).

For asthma, the importance of a multi-pronged approach in successful asthma control has been central in the recommendation of various international guidelines. The effectiveness of pharmacological treatments such as usage of steroid inhalers can be measured direct or indirect impact on the underlying condition, and measures such as lung function tests, and frequency of severe attacks requiring hospitalisation or emergency department. However, interventions such as patient education and counselling may have broader impact on the patient. For example, the recipient of such interventions may acquire self-management skills or the confidence to cope with having

asthma, and this would not be directly reflected by these measures. Therefore, HR-QoL measures could play an important role in proving the importance of such interventions as it measures how the patients perceive such interventions has improved aspects that are important to them (Matza et al., 2004).

1.3.2 How do we measure quality life?

HRQL instruments may be categorised into disease or condition specific instruments and generic or general-purpose instruments (Juniper et al., 1996a). A generic instrument has an advantage of providing a common method of measurement that facilitates comparison of HRQL impairment across different conditions (Connolly et al., 1999; Juniper et al., 1996a; Richards, Jr. & Hemstreet, 1994). However, these generic instruments may not be responsive enough to detect small but significant changes in HR-QoL (Rutten-van Molken et al., 1995).

Disease specific instruments are more sensitive. That is, the instrument can detect smaller, but important changes characterised by a certain disease that may not be detectable by a generic instrument (Connolly et al., 1999; Juniper et al., 1996a; Rutten-van Molken et al., 1995). There were some debates on which instrument is more important in measuring paediatric asthma. Richards and Hemstreet concluded that both serves to complement each other in asthma QOL research and should be included. If the amount of information required may overburden the patients and a choice has to be made, asthma specific instruments should be given higher priority (Richards, Jr. et al., 1994).

1.3.3 Why can't we just ask the parents?

Proxy-reports are not always valid and reliable, and have reported to be more accurate in areas pertaining to physical symptoms rather than in the more subjective areas such as emotions and feelings (Erickson et al., 2002; Guyatt et al., 1997; Juniper et al., 1996a; Marks et al., 1993). Therefore, caution need to be exercised if proxy report is used (Eiser & Morse, 2001).

1.3.4 What are the considerations in choosing a quality of life questionnaire? Are there any differences for children's and adults?

Measuring HR-QoL in children has been likened to "hitting a moving target". Children of different age groups will have different levels of cognitive development in terms of vocabulary, recall period, or the ability to understand certain concepts that are being asked(Matza et al., 2004; Rebok et al., 2001). Therefore, questionnaires need to take into account the children's cognitive ability and the minimum skills which would be required (Juniper et al., 1997a). The challenge of using and producing valid and reliable HR-QoL measures is also compounded in societies which are multi-racial, multi-cultural and multi-lingual society like Singapore. Designing questionnaires for self completion by children of younger age groups could be difficult. The official language which the children learn in school is frequently different from the language the children speak at home. For example, although English is the common language *(lingua franca)* for communication in Singapore, less than half of children aged 5-14 years speak English at home (Census of Population Office Department of Statistics,

2000). Situations may arise where the children are more comfortable speaking in one language, and reading in another language. Therefore, due diligence has to be exercised in choosing an instrument so that it is acceptable and usable, especially in the younger age group. So far, there are very few published studies on cultural adaptation and validation of a paediatric HR-QoL instrument in Asia, with only one published study for asthmatic children in Singapore (Clarke E. et al., 1999).

1.3.5 Why and how do you conduct a cross-cultural adaptation and validation?

Cross cultural adaptation and validation of instrument is the account for the majority of existing HR-QoL instruments. Most HR-QoL instruments which are currently in used have been developed, tested and validated in one country before being adapted and translated to another country, culture or language (Anderson RT et al., 1996). Cross cultural adaptation and validation is a practical way of acquiring and using a HR-QoL instrument. Other than having to reinvent the wheel and therefore save the cost and time associated with a full scale development, cross cultural adaptation of instruments allow results from different countries and studies to be compared.

The general procedures of cross-cultural adaptation are as follows (Guillemin et al., 1993; Herdman et al., 1998; Wild et al., 2005):

- Forward translation- It is generally agreed that two or more translators, ideally native speakers of the targeted language, are needed to translate the source instrument into the targeted language (Guillemin et al., 1993).

- Reconciliation- The differences between the two forward translations are discussed, and a consensus version is obtained. This may and may not involve a third independent translator.
- Back translation- The consensus version would be back translated with at least another two translators, to detect any misunderstandings or deviation from the conceptual meaning of the questionnaire.
- Back translation review- The back translation is compared against the original questionnaire. Discrepancies identified should be followed up, and revisions may need to be made to the forward translation to improve the clarity of or precision of the translation. Clarification of the concepts in the questionnaire may also need to be obtained from the developer whenever this was possible.
- Harmonization-This step has been suggested to ensure inter-translation validity of the instruments, and allowing for reliable pooling of data from randomized controlled trials (Wild et al., 2005). In some guidelines, this is not outlined as a separate step, but as a process that is incorporated in each step of the translation.
- Cognitive debriefing or pilot testing- The main purpose of this step is to ensure that the translation is understood, and the questionnaire is acceptable to the target population. Respondents would be asked to complete questionnaire, followed by a structured interview to find out what the item means to them.

A questionnaire which has been cross-culturally adapted and translated need to be validated before being used more widely in the clinical or research setting. A valid instrument is an instrument which measures what it is supposed to measure (Fayers PM

& , 2000). Various aspects of an instrument would be examined, and data need to be collected for validation. Here is a brief description of the various aspects:

- Content valid refers to the degree to which an instruments' contents i.e. items are representative and relevant to what it is supposed to measure.
- Face validity refers to the degree to which items on an instrument appear to agree the intended topics clearly and unambiguously on the face. Like content validity, qualitative methods such as focus groups and interviews with patients and experts are to assess the validity.
- Construct validity refers to the degree to which and instrument measures the construct which it had been designed to measure. The components of construct validity include discriminant validity, known-group validity, criterion validity and convergent validity.
- Reliability of an instrument refers to the reproducibility of its results. In cross-cultural adaptation, internal consistency and test-retest reliability are two properties of which are often evaluated. Other related properties including the sensitivity and responsiveness of the instrument. Internal consistency is frequently one of the first properties measured in cross cultural adaptation as data could be collected in a cross-sectional study, and used as an estimate of the test-retest reliability of the instrument. Cronbach's alpha coefficients are usually reported, and values about 0.7 are generally considered acceptable for group comparisons. To assess individual subjects, values above 0.9 are recommended (Nunnaly JC & Bernstein IR, 1994).

1.4 RESEARCH QUESTIONS, AIMS, AND THESIS ORGANISATION

From the prevalence and healthcare utilization data which are available about childhood asthma in Singapore, it was hypothesized that the burden of asthma in terms quality of life impact would be significant to both the children and parents. The high morbidity and preventable hospitalisations suggested that there might be a missing link in the management of asthma in Singapore, which as been ranked one of the best healthcare systems in the world by WHO (World Health Organization: 2000) . Asthma is a treatable disease as effective pharmacological agents are available, and access to healthcare is perceived to be good in Singapore. Therefore, the weakness could lie in the ability of parents and patients to manage their asthma effectively. Therefore the current thesis focuses on the patient's perspective in asthma management.

The research of the studies in this dissertation and its organisation could be summarized as follows:

1. Is there a lack of asthma knowledge among parents of asthmatic children in Singapore? Which are the groups that should be prioritised in patient education delivery? In Chapter 2, we compared the level of asthma knowledge, inhaler techniques and health outcomes in terms of the patients' absence from school due to asthma between parents from a specialist and a general clinic in the hospital.
2. How do patients and parents perceive asthma and its medications? How is actually managed at home? What are the factors which support the effective management, and what factors act as a barrier? The purpose of answering these questions is obtaining in-depth understanding of the patients' view point so that patient

educations could be tailored, and more effective. Chapter 3 reported the focus group sessions which were conducted in different ethnicities and language to answer these questions.

3. How do the public perceive asthma? Are there common misunderstandings or areas of ignorance which could affect the outcomes of patients with asthma? What should be targeted in public education efforts? Chapter 4 documented a public survey about asthma, where the perceptions of the public and prevalence of certain views about asthma and its management are discussed.
4. Can asthma quality of life questionnaire for paediatric and adolescent asthma be adapted from a Western country for patients in Singapore? We set the criteria that the instrument adapted in this manner should not only be valid and reliable, but also simple enough to be completed by patients with limited literacy and from lower socioeconomic groups, as these groups have been noted to be have the most severe asthma in Singapore. Two chapters were dedicated to this; Chapter 5 reported the validation of CAQ-B for younger children, while Chapter 6 reported the validation of CAQ-C for teenagers.
5. The last chapter of this dissertation recapitulates the research questions and major findings of these research projects. The contributions of the project and research question that were elicited from these findings and ought to be further studied in the future are briefly discussed.

Chapter 2. Parents' perception of asthma: A comparison of the Knowledge and Perception about Asthma between Caregivers from General and Specialist Clinic at a Paediatric Hospital.

2.1 INTRODUCTION

Despite significant advancement in the understanding of the pathophysiology of asthma and availability of effective pharmacotherapy, morbidity due to childhood asthma is still high (Smith et al., 1997; Fuhlbrigge et al., 2002). This has affected the children's quality of life and increases medical care utilization (Smith et al., 1997; Chew et al., 1999; Townsend et al., 1991).

Like any other chronic diseases, successful childhood asthma management is highly dependent on the patient's self-management skills; which could be affected by many factors (Clark & Gong, 2000; Marino, 1996; Milgrom H et al., 1994; Warman, 2000; Weinstein, 1995). These include patients' and caregivers' knowledge of the disease, awareness of trigger factors and inhaler technique. Hence, good knowledge of asthma is a cornerstone in effective self-management and a deciding factor in fostering concordance between healthcare providers and patients or caregivers.

Among other factors, asthma knowledge is amenable with appropriate education. Therefore, international guidelines such as National Asthma Education and Prevention Programme (NAEPP) stressed the importance of educating patients to become good partners to healthcare providers in effectively managing their condition (National Asthma Education Program expert panel report., 1997; Global Initiative for Asthma., 2002). The need for proper patient education has also been demonstrated in Singapore in previous studies (Lim et al., 1996; Tan, 1999; Wong et al., 1994).

Among these, the study conducted at a specialist respiratory clinic of a tertiary paediatric hospital specifically evaluated the impact of a one-to-one education intervention on asthma knowledge and outcomes. Asthma knowledge, metered dose inhaler (MDI) technique, self-reported compliance and symptom scores did improve significantly after the intervention (Tan, 1999; Lim et al., 1996). This highlighted that an educational intervention can still contribute to improve disease management even in specialist clinics that were expected to provide better patient care for chronic diseases (Alessandro et al., 1994; FitzGerald, 2001; Sperber et al., 1995).

The level of asthma knowledge might be even lower in a non-specialist setting, as demonstrated by the findings of a 1992 study conducted in government polyclinics showing the elderly and the less educated had especially poor knowledge and MDI techniques (Wong et al., 1994).

Based on these studies, we would expect parents or caregiver of children receiving care from non-asthma specialists were likely to have poorer knowledge about asthma and its management than those treated by a specialist. If this is the case, tailored education interventions would be even more important to this group, and could have possibly a bigger potential in improving asthma management and outcomes.

In order to verify the above hypothesis, the present study was conducted in the general paediatric clinic in the same hospital as the previous study (Tan, 1999; Lim et al., 1996). Unlike the patients in the specialise clinic who were followed-up by respiratory specialists, patients in the general clinic were under the care of non-specialist medical officers who ran the clinic on a rotation basis.

The main objective was to determine whether any differences existed in the perception of asthma and its medications, or types of barriers encountered between patients and caregivers attending the general paediatric and the specialist respiratory clinics. The information would serve in deciding whether there is a need for targeted education, as well as an important platform to formulate appropriate educational programmes that cater to the specific needs of patients with different disease severity or socioeconomic background if the need exists.

2.2 METHODS

2.2.1 Subjects and study settings

The study populations were children and caregivers attending the general paediatric clinic (GPC) in the Paediatric Medicine Department of KK Women and Children's Hospital (KKH), the largest medical facility providing specialised care in the areas of neonatology and paediatrics in Singapore.

Patients attending GPC were usually either on follow-up after being discharged by the wards or referred from the polyclinics run by the government. A majority was subsidised who paid lower rates as a part of the bill were paid through government subsidies.

Eligible subjects were identified through their medical records or referred by their treating physicians. Inclusion criteria were: (1) the patients were equal or less than 16 years old and prescribed asthma medication, and (2) caregivers were able to converse in simple English, Mandarin or Malay. Patients who had other medical conditions that

could complicate their asthma condition and therapy, e.g. diabetes, certain heart conditions and other concurrent lung diseases were excluded.

These criteria were identical to the study previously conducted in the specialist respiratory medicine paediatric clinic (SRC) (Tan, 1999), except the inclusion of caregivers who were not able to read Mandarin or English but able to converse in either English, Mandarin or Malay to ensure a more representative sample. The amendment was formulated from the observation that many of the parents and caregivers in the general paediatric clinic had lower educational level compared to the specialist clinic and many were Malays or Indians.

2.2.2 Procedure

The treating physician explained the aims and procedures of the study to the potential subjects. After informed consent, the subjects completed a self-administered questionnaire (identical to the questionnaire used in the specialist clinic study) (Tan, 1999), had their inhaler techniques assessed, and counselled. The investigators were present to clarify any queries or to assist in filling up the questionnaires as necessary. For those who could not read, the interviewers would read out the questions ad verbatim and would translate from English to Malay or Chinese if necessary. The subjects' medication records were retrieved to validate the information obtained from the interview. Eligible subjects who missed their clinic appointments were contacted through phone and the purpose of the study was explained. Those who agreed to participate were interviewed during a home visit at a mutually convenient time.

2.2.3 The Questionnaire and Scoring

There were 2 sections in the questionnaire. Section A of the questionnaire measured the caregiver or the patient's perception of asthma as a disease by assessing their knowledge on the pathophysiology, symptoms and triggers of asthma, while Section B assessed their understanding of asthma medication, including the mode of action, usage and side effects of the 2 main classes of asthma medication.

The respondents had a choice of 3 responses: "Agree", "Disagree" or "Not sure" to statements in the questionnaire. Points were allocated based on the relative importance as identified by a paediatric respiratory physician (OMC) of the statements in affecting patients' asthma management. Important statements were given 2 points per correct answer while others were given 1 point each. The corresponding points were deducted for wrong answers. "Not sure" responses were not given any points.

Each child's inhaler technique was assessed and scored using a scoring system adapted from a study by Smith (Smith, 1988).

2.2.4 Data and Statistical Analysis

Results obtained were compared with the corresponding values obtained in the previous study using unpaired t-test (Tan, 1999). Chi-square or Fisher exact tests were used for other comparisons. The levels of statistical significance were set at $p \leq 0.05$ except for chi-square or Fishers' exact tests involving the items in the questionnaire where statistical significance were set at $p \leq 0.005$.

Subgroup analyses were carried out based on criteria such as age, race, language spoken, income, educational level and usage of preventative medicines. The differences between the groups were analysed using one-way ANOVA or independent t-test. All analyses were performed using Statistical Package for the Social Science (SPSS) version 11.5.

2.2.5 Inter-rater standardisation

To ensure comparability between the results, an inter-rater test was conducted in 6 patients randomly chosen for the inhalation technique assessment involving the MDI via spacer with the investigator studying the general clinic patients and the investigator for the specialist clinic study took part in the exercise.

2.3 RESULTS

2.3.1 Inter-rater standardisation

The mean kappa values obtained between these two investigators was 0.86, (0.59 to 1.0). Kappa values between 1 and 0.8 means very good agreement, 0.61 to 0.80 means good agreement and 0.41 to 0.60 indicates moderate agreement (Altman, 1991).

2.3.2 Patient & Caregiver Characteristics

In total, 46 subjects consented and participated in the study. However, only 45 subjects were included in the final analysis. One was dropped as the medical records cast doubt of a genuine case of asthma.

Fifteen subjects were interviewed at home as they had defaulted their clinic appointments citing reasons such as financial difficulties, bad weather (rainy day) and forgetfulness. They often supported their decisions by pointing out that their child was relatively better and therefore seeing a doctor was not necessary. Characteristics of patients investigated in the general paediatric clinic (GPC) and specialist respiratory clinic (SRC) (Tan, 1999) are in as shown in Table 2.1. Caregivers in the GPC were had significantly lower income and educational levels, tend to be younger, and less likely to be in professional or managerial positions than caregivers in the SRC (Table 2.2).

All questionnaires except one (filled by an adolescence who was taking care of himself) were filled by the caregivers with or without the assistance of the investigator. Thirty-five (78%) English and 10 (22%) Chinese questionnaires were used. Of the 35 English questionnaires used, 6 (17%) had to be read out by the investigator, either in English, Malay or Chinese.

Table 2.1: Characteristics of patients investigated in the general paediatric clinic (GPC) and specialist respiratory clinics (SRC).
* One missing value.

	GPC	SRC	P
Sample size,n	45	42	
Patient sex, n (%)			ns
Female	18(40)	15(24)	
Male	27(60)	27(64)	
Race, n (%)			
Chinese	27 (60)	34 (81)	0.03
Other ethic groups	18(40)	8(19)	
Age(years)* N=44			0.03
Mean (SD)	6.25(±3.09)	7.64(±2.83)	
Median	6	8	
Mode	4	5,9	
Medication usage, n (%)			<0.001
Currently on preventers	26(58)	42 (100%)	
Tried but currently not using preventers	8(18)		
Never tried any preventers	11(24)		

Table 2.2: Sociodemographics of the caregivers in the general paediatric clinic (GPC) and specialist respiratory clinics (SRC)

		GPC	SRC	P value
Sample size		45	42	
Relationship				ns
	Mothers	29(65)	36(86)	
	Fathers	12(27)	5(12)	
	Others	4(7)	1 (2)	
Sex				ns
	Male	14(31)	35 (83)	
	Female	31(69)	7 (17)	
Age				0.008
	<20	4 (9)	0	
	20-35	18(40)	7(17)	
	36-45	20(44)	30(71)	
	>45	3 (7)	5(12)	
Languages Spoken				ns
	Mandarin	20(44)	20 (48)	
	English	31(69)	34 (81)	
	Malay	11(24)	7 (19)	
	Tamil	5(11)	3 (7)	
	Dialects	1(2)	2 (5)	
	Unable to speak English or Mandarin	12(27)	Not known	
Educational level				<0.001
	Primary education or less	27(60)	4(10)	
	Completed secondary education	12(27)	19(45)	
	Post-secondary education	6(4)	16(38)	
	Not stated	-	3(7)	
Profession				
	Technical	7(16)	3(7)	0.02
	Clerical	6(13)	6(14)	
	Professional/managerial/self-employed	5(11)	13(31)	
	Housewives	17(38)	18(43)	
	Others	10(22)	2(5)	
Family Income				<0.001
	<$1000	12(27)	2 (4)	
	$1000-2999	26(58)	13(31)	
	>$3000	7(16)	25(60)	
	Not stated	-	2 (5)	

Statistical significance set at $P<0.005$, $P<0.05$ are shown

2.3.3 Knowledge

The mean total score for Sections A and B was 21.1 ± 8.7 out of a maximum 48 points (n=45) or 44.0 ±18.8%. This was lower than the results obtained in the specialist clinic (26.6 ± 7.3, n=42) by an average of 5.5 points (p=0.01). This difference means that on average, a caregiver from the SRC clinic answered correctly two important statements or 5 usual statements more than the average caregiver in GPC.

Table 2.3: Summary of scores obtained in the general paediatric clinic (GPC) and specialist respiratory clinic (SRC)

	GPC	SRC
	Mean score ± SD (%)	**Mean score ± SD (%)**
Asthma knowledge* (22 points)	58.7 ± 20.8	68.5 ± 14.8
Medication understanding* (26 points)	31.6 ± 24.7	44.5 ± 22.2
Total (48 points)	44.0 ± 18.1	55.5 ± 15.3

*P=0.01

2.3.3.1 Section A - Parental perception of asthma

Compared to their counterparts in the SRC (scored 15.1±3.2 out of 22 points), the caregivers in the GPC (scored 12.9 ±4.5) had a poorer understanding of asthma (p= 0.01). Table 2.4 listed the percentages of parents or caregivers who could answer correctly on the various statements in Section A in the questionnaire.

Table 2.4: Percentage of respondents providing a correct answer for the section on asthma perception

Statements		Ans	SRC	GPC	Difference	P
Cause	Many things can trigger asthma attacks*	T	97.6	95.6	-2.0	NS
	Born with extra-sensitive airways	T	76.2	46.7	-29.5	0.005
	A psychological illness	F	59.5	53.3	-6.2	NS
	Poor nutrition is a cause	F	52.4	44.4	-8.0	NS
Symptoms	Wheezing	T	97.6	93.3	-4.3	NS
	Shortness of breath	T	95.2	100.0	4.8	NS
	Chest tightness	T	85.7	73.3	-12.4	0.15
	Coughing for more than one week	T	76.2	82.2	6.0	NS
Cause of symptoms	Tightening of airway muscles	T	95.2	93.3	-1.9	NS
	Excessive mucus blockage	T	81.0	77.8	-3.2	NS
	Swelling of inflamed airways	T	69.0	51.1	-17.9	NS
Treatment	No cure even with treatment*	T	31.0	35.6	4.6	NS
	Controllable with proper treatment*	T	100.0	86.7	-13.3	0.01
	Traditional Chinese medicines can cure it	F	33.3	20.0	-13.3	NS
Seriousness	Attacks can be fatal*	T	97.6	80.0	-17.6	0.01
	Asthmatics should not exercise at all*	F	85.7	86.7	1.0	NS
	No warnings prior to attacks, not preventable	F	45.2	53.3	8.1	NS

Chi square tests of number of correct answers vs. incorrect or unsure options were conducted. Statistical significance was set at $p<0.005$, but all p values less than 0.01 were displayed. Items which had been considered as "important statements" and awarded 2 points are denoted with an *sign.

Significantly more caregivers in the SRC agreed that asthmatics are born with more sensitive airways (47%-GPC vs. 76%- SRC, $p<0.005$). More than 40% of caregivers from both clinics wrongly believed that asthma can be cured. About two third in the GPC and half in the SRC were unsure whether traditional Chinese medication could cure asthma.

In the GPC, less caregivers realised that an asthma attack could be fatal compared to caregivers in the SRC (80% vs. 98%; p=0.01). However, all caregivers surveyed in the SRC believed that asthma is controllable with proper treatment compared to only 87% in the GPC (p=0.01).

2.3.3.2 Section B (Knowledge of asthma medications)

The mean score for Section B was 8.2± 6.4 (31.6%) out of a maximum of 26 points. This section had a wide range of 28 points (-6 to 22 points) with a median of 9 and mode of 10 points. Table 2.5 listed the percentages of parents or caregivers who could answer correctly on the various statements in Section B in the questionnaire

Table 2.5: Percentage of respondents providing a correct answer for the section on knowledge of asthma medications

Statements		Ans	SRC	GPC	Difference	P
Classes	Preventers and relievers the basic groups*	T	95.2	91.1	-4.1	NS
Roles of relievers and preventers	Relievers relaxes tightened airway muscles*	T	85.7	88.9	3.2	NS
	Preventers reduce airway inflammation*	T	73.8	73.3	-0.5	NS
	Preventers are for long term use*	T	71.4	53.3	-18.1	NS
	Preventers often take weeks to show benefit	T	73.8	48.9	-24.9	0.02
	Preventers are useless once an attack has begun*	T	38.1	37.8	-0.3	NS
Inhaled medicines	Faster onset than oral medicines	T	85.7	77.8	-7.9	NS
	More effective as medicines goes to lungs*	T	85.7	80.0	-5.7	NS
	Cause more side-effects*	F	47.6	35.6	-12.0	NS
	Home nebulisers more effective than others	F	7.1	18.2	11.1	0.125#
Inhaled steroids	Can slow a child's growth*	F	31.0	13.3	-17.7	0.05
	Risk of dependence & addiction in long-term	F	33.3	26.7	-6.6	NS
	Only used if condition not improved with others	F	50.0	46.7	-3.3	NS
Treatment choices	All cough mixtures useful for coughs in asthmatics	F	61.9	37.8	-24.1	0.024
	All children gets exactly the same asthma treatment	F	42.9	33.3	-9.6	NS
Long-term use	Long term medications harmful for children	F	21.4	17.8	-3.6	NS
	All medicines should be stopped once condition improves*	F	76.2	44.4	-31.8	0.003

Chi square tests of number of correct answers vs. incorrect or unsure options were conducted. Statistical significance was set at $p<0.005$, but all p values less than 0.01 were displayed. Items which had been considered as "important statements" and awarded 2 points are denoted with an *sign.

p=0.005 when a scoring system of 1 point for correct answer, 0 for the "unsure" option and -1 for wrong answers.

2.3.4 Inhaler Technique

Thirty nine of the 45 subjects studied in the GPC were using a spacer with their metered-dose inhaler (MDI). One was not on any inhalers during the study. The others were using MDI directly or dry powder inhalers such as Easyhaler® or Accuhaler ®.

The technique of using a MDI via a spacer was assessed for 38 patients in GPC (as against 35 patients previously performed in SRC). The caregivers were asked to rate their own inhaler techniques before being tested. No correlation was found between self-rating and test scores obtained. Test scores were also not correlated to either the asthma perception or knowledge of medication scores. Ninety percent (34 out of 38) of caregivers from GPC and 97% (34 out of 35) of caregivers from SRC rated their own technique in the range of "fair to very good" on a 1 to 10 visual analogue scale (1=very poor, 5= fair and 10= very good technique). However, only 37% in GPC and 23% in SRC performed all the critical steps correctly and passed the test ($p=0.05$, Mann Whitney test). Most of the SRC clinic patients who failed forgot to shake the canister before using or before discharging the next puff (Table 2.6).

Table 2.6: Percentages of patients getting each MDI via spacer step correctly, getting all the critical steps correctly and getting all the critical steps plus gargling correctly.

Steps	All patients using MDI via spacer		
	GPC (N=38)	**SRC (N=35)**	**P**
1) Correct upright hold of inhaler, shakes inhaler and removes the cap.	84	74	NS
2) Correct and tight attachment of the inhaler to the end opposite to the mouthpiece of the assembled spacer.	100	100	NS
3) Slow and deep breathing into the spacer 2-3 times (with lips closed around the mouthpiece and spacer horizontal).	92	100	NS
4) Discharge of the inhaler once onto the spacer, followed by slow and deep inspiration through the mouth.	87	97	NS
5) Breathe in and out of the spacer about 5 times.	76	63	NS
6) If a second dose is prescribed, there should be a lapse of about 30 seconds to 1 minute before the next puff. #	40	91	<0.001
7) Shake the canister again before discharging the next puff into the spacer.	71	31	0.01
8) For MDI containing steroids – rinse the mouth with water after using the inhaler.#	54	27	0.05
Passed all the critical steps	37	23	NS
	Patients using a MDI containing steroid		
	GPC (N=28)	SRC (N=26)	
Passed the critical test and also gargled	11	8	0.85

# denotes those steps that are less critical in the usage of inhalers.

2.3.5 Impact of asthma on school

Out of the 36 school going patients in the GPC, 22 (61%) had been absent from school in the last schooling month due to asthma compared to only 9 out of 39 (23%) in the SRC, (p=0.001). The median number of school days missed was 1 day (range 1-7 days) in the GPC vs. 0 day (range: 0-10 days) in the SPC ($p<0.05$, Mann-Whitney test). The most common reasons for missing school in the GPC were the child appeared weak and tired (n=21, 62%) followed by high fever and persistent coughing (n=20, 59 %), (Table 2.7).

Table 2.7: Impact of asthma on school attendance: school absenteeism and conditions that parents would absent children from school

	GPC	SRC
Number of School Going Children	n=36	n=39
Absented at least one day in the past schooling month	22(61%)	9 (23)
Days of absence for all school going children@	n=33	n=39
Total number of days absence	50	35
Mean	1.5±1.8	0.9±2.0
Median# (range)	1 (0-7)	0 (0-10)
Number of days of absence for children affected@	n=19	n=9
Mean	2.6±1.6	3.9±2.6
Median	2	3
Range	1-7	1-10
Reasons for absence*	n=34	n=39
(a) Child has stuffy nose but show no wheezing.	2(6)	1(3)
(b) Child has a little wheezing that goes away after some medication.	4(12)	5(13)
(c) Child shows difficulty in breathing.	17(50)	33(85)
(d) Child has a high fever and persistent coughing.	20(59)	39(100)
(e) Child shows wheezing / coughing that still continue or worsen an hour after taking the medicine.	17(50)	38 (97)
(f) Child appears tired and weak.	21(62)	29(74)
(g) Others	4(12)	
i) Not responding after one night of medications	1(3)	
ii) On medical certificate from doctors	2(6)	
iii) Fear that condition may infect other children	1(3)	

@ 3 subjects with absence from school did not provide number of days of absence

* Excludes missing values, subjects were allowed to choose more than one answer for the reasons #p=0.01, Mann Whitney test

2.4 DISCUSSION

Some studies had suggested that asthmatics tend to fare better when treated by specialists rather than generalists (Donnelly et al., 1987; Farber et al., 2003; Juniper, 1999b; Nouwen, 1983b; Spykerboer et al., 1986; Tan et al., 1999; Testa & Simonson, 1996b; Testa et al., 1996a). However, whether these patients know more about their disease and medications than other groups was yet to be demonstrated. In this study, caregivers from the GPC did show a statistically significant poorer understanding of asthma and the medications.

This difference may contribute to one of the patient relevant outcomes with children attending the GPC lost significantly more school days to asthma than children attending the SRC. It is usually assumed that children seeing generalists have milder asthma while more serious cases are referred to and cared by specialists. Therefore, our observation could be attributed to either poorer asthma control in the GPC or underestimation of the patients' severity.

In contrast to GPC patients who were seen by different medical officers rotated through the clinic, patients in the SRC were followed-up by their regular specialists at regularly scheduled visits. Regular follow-up by the same physician would allow better doctor-patient rapport and trust, thus enabling doubts and queries to be clarified. This could partly explain why although many parents from both clinics were concerned about safety of long-term medication (especially inhaled steroids), significantly less parents from the specialist clinic agreed that to the statement that "all medications should be stopped as soon as the child gets better".

The difference between the perceptions of parents in these two clinics could also be further explained by the fact that accessibility to a specialist did not solely depend on the actual severity of the child's asthma but also the parent's efforts to get a referral and their ability to pay for the service. In Singapore, a patient could circumvent the usual referral system and request to see a specialist in a public hospital by paying higher fees as a private patient. As such, it is possible the parents in SRC were more likely to believe in the benefit of specialist care and motivated as partners in asthma control.

Indeed, more patients attending the GPC were from disadvantaged socio-economic backgrounds and minority ethnic groups with 27% of subjects in GPC (vs. 7% in SRC) came from families with a total income of less than S$1000 per month (US$589). Affordability of continuous medical care would have been a major concern as reflected by the significant number of interviews conducted in the patients' homes due to high default rates in the GPC. According to some parents, the main reason they defaulted appointments was the inability to bear medical expenses such as consultation fees and medication costs as well as the indirect costs such as transportation and taking time off work. Given such circumstances, taking an afternoon off work to bring an apparently well child for follow-up was not a priority. This is further augmented by the fact that 4% of GPC caregivers considered "cheaper" price as one of the most important considerations for their medication choice, compared to none from the specialist clinic.

Besides the above observations, a close look at the perception and knowledge of asthma and medications highlighted certain similarity and difference between the two groups. While most of the differences are likely to be caused by the disparity in their

socio-economic background, the severity of the child's condition and medical care received, some popular misconceptions and local beliefs regarding asthma would explain the similarity in their perceptions. One major difference would be their views of seriousness of asthma and airway hypersensitivity. During the counselling session after the survey, some GPC caregivers had difficulty grasping of how airways hypersensitivity and swelling could be related to the observed asthma symptoms. Many were in a denial state as they believed that one could not get asthma unless someone else in the family was having it, and the symptoms in their children were caused by certain food and drinks, rather than airway hypersensitivity.

The misbelieve would be a potential root of poor compliance (Farber et al., 2003). Like other studies, a high proportion of parents from both clinics were concerned and sceptical about the safety of long-term medication and steroid inhalers (Donnelly et al., 1987; Spykerboer et al., 1986). Perhaps due to their poorer understanding of hypersensitivity and chronic airway inflammation, more GPC caregivers believed all asthma medications should be stopped as soon as their child gets better.

Another notable observation was that the majority of patients from both clinics used MDI with a spacer incorrectly. Although the inhaler technique passing rates in our studies were low, they were higher than reported in previous local studies (Tan et al., 1999; Wong et al., 1994). Nevertheless, the higher passing rates among GPC patients should not be interpreted as they had good inhaler techniques. These scores did not reflect the "quality" of mistakes nor distinguish slight inaccuracies from gross mistakes that prevented patients from receiving any potential benefits from medications prescribed.

In addition, some GPC patients claimed that they were following the doctor's instructions but had either misunderstood or remembered wrongly, resulting in their use of salbutamol as a preventer or beclomethasone MDI to avert attacks. These findings demonstrate the inadequacy of verbal instructions alone. The patients should be asked to demonstrate their technique with a placebo inhaler during clinic visits, as overtime, even the most compliant and well-trained patients may start to make mistakes, unless the techniques are consistently reinforced.

This study has several limitations. This study was conducted a year after the SRC study. A programme which was initiated to improve inhaler technique was ongoing in both areas during the year and it may have influenced any differences in knowledge and inhaler technique. Emergence of more pronounced trends of difference in opinions between the two clinics could have been limited by the small sample. Furthermore, three out of six respondents in the GPC who needed extensive assistance in filling in the questionnaire had scores at the high end (28 to 30) and lower than average number of "unsure" answers. This might have increased the overall score in the GPC and hence underestimated the difference between the two studies. A larger study with more outcomes details would help to examine whether differences in knowledge levels are also accompanied by poorer health and quality of life.

2.5 CONCLUSION

Overall, our results demonstrate some common misconceptions among caregivers that may prevent the asthmatic children from obtaining the optimal benefits from the management of their disease. In addition, the deficiency in knowledge is more

pronounced in caregivers from the GPC, who happen to be more likely to come from disadvantaged socio-economic backgrounds and minority ethnic groups. This would suggest that specially tailored education intervention could play a role in achieving better outcomes in the patients. However, an effective education intervention must be of relevance to the subjects involved. Messages must be put across in a manner which could be understood and accepted easily by patients and compatible with their educational level and cultural beliefs.

Besides getting key information across effectively, concordance should be practiced whenever possible, to close the gap between the point of view of health care providers and patients when prescriptions are given and self-management plans are designed. Patients' wishes and views should be respected and incorporated whenever possible. Allowing patients to continue some of their benign "unscientific" practices which originated from their cultural or health belief system may encourage more open communications and may enable the healthcare provider to detect other practices which may be harmful. Nevertheless, it is through understanding the patients and their caregivers point of views and how asthma impacted them that we can work on effective strategies to manage asthma in a holistic manner in the future.

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Chapter 3. Perception of Parents and Patients about asthma, Coping Strategies and Barriers Encountered in Asthma Management:
A Qualitative Approach to Enhance Understanding

3.1 INTRODUCTION

Asthma is a chronic respiratory illness affecting 1 in 5 of children in Singapore (Goh et al., 1996; Wang et al., 2004) and about 1 in 20 adults in Singapore (Ng et al., 1994). It was the second most common condition for hospital discharges in children under 14 years old, and the 6th most common condition seen in the primary health care level (Chew et al., 1998). One possible reason for the high morbidity observed in this treatable condition is the inadequate knowledge about asthma on the part of parents and patients, resulting in sub-optimal management of patients at home (Wong et al., 1994).

Since then, new asthma education initiatives have been implemented across the country, and have been reported to significantly reduce the rate of emergency department visits and hospitalizations (Prabhakaran et al., 2006; Lim, 2003). However, the success of these interactive education strategies to change the knowledge or perceptions of patients in various aspects of asthma varied, and this had been attributed possibly to patients' strong-rooted beliefs (Prabhakaran et al., 2006). Studies in the United States among black and Navajo (North American Indians) patients showed that the barriers to quality asthma care was related to their asthma perceptions and health beliefs, not access to care issues (Mansour et al., 2000; Van Sickle et al., 2001). Furthermore, it has been reported that how patients view their asthma medications could affect their willingness to adhere to self-management plans and ultimately their asthma control (Osman, 1997). Therefore, it is important for healthcare providers to not only have a deep understanding of the parental and patient perception of their asthma and asthma medication, but also other factors which might affect or influence their beliefs and actions.

In the past decade, most qualitative studies on asthma have been conducted in the West, particularly in the United States and United Kingdom (Cane et al., 2001; George et al., 2003; Kieckhefer & Ratcliffe, 2000; Mansour et al., 2000; Peterson-Sweeney et al., 2003; Valerio et al., 2006; Van Sickle et al., 2001). As socioeconomic factors like culture and ethnicity are important factors which affect a person's health beliefs, it is important that such research be conducted in an Asian environment. Asia has rich histories and cultures with deeply rooted health beliefs which are still held and widely practiced today. These could potentially contribute to significant differences in how asthma and its treatments are viewed and managed (Tam, 2002).

Singapore, which boasts a world class health care facilities, but at the same time is a multi-ethic, multi-cultural country made up of some of the main ethnicities in Asia; namely, Chinese, Malay and Indian would be an ideal place to conduct such studies (Connett & Lee, 1994). In addition to augment what is already known from similar studies conducted in western countries, the insights obtained would be able to contribute to asthma management among Asian paediatric patients. As this is an exploratory study, a qualitative approach which could provide relevant, rich and in-depth data of a reasonable breadth would be ideal. As such, the focus group method was deemed most appropriate (Morgan DL., 1988; Rice PL & Ezzy D, 1999).

The aim of this study was to explore the perceptions of parents and patients of asthma, coping strategies employed and the barriers encountered in asthma management. The findings would provide important information for health care providers to tailor more

effective counselling and education approaches, and equip patients and parents as effective asthma management partners.

3.2 METHODS

3.2.1 Participants and recruitment

Participants were recruited from a few sources: (1) Parents of children attending follow-up at the specialist respiratory clinic at KKH; (2) Parents of children attending a high risk asthma clinic in KKH under Singapore National Asthma Program; (3) Referral from polyclinics and other institutions; and (4) Participants who found out about the study through friends or posters which had been put up in the waiting areas in polyclinics and KK Hospital.

Prior to attending the focus group session, the potential participants would be briefed and screened by an asthma resource nurse to ensure they met the inclusion criteria. They would also be briefed by the nurse about the purpose of the focus group, and how the focus group would be conducted. Participants who met the inclusion criteria and willing to participate would be invited by the nurse to attend the relevant sessions at a secluded room at KKH, or in a community club on a Saturday afternoon. The project had been approved by the institutional review board of KKH.

3.2.2 Inclusion criteria

1. Participant could either be a patient who has asthma (aged 13 and above and was responsible for taking care of their asthma medication), or a parent of children (aged between 1-16 years) with asthma
2. The diagnosis of asthma had been confirmed by doctors

3. Visited a doctor at least 2 times in the past 12 months for asthma related problems
4. Prescribed at least one of these medications
    - Bronchodilator-salbutamol (Ventolin ™) (either oral or inhaled)
    - Theophylline
    - Inhaled corticosteroids like beclomethasone dipropionate (Becotide™) or budesonide (Pulmicort ™)
    - Salbutamol with a nebulizer

3.2.3 Focus group format

The focus group procedures followed the commonly used principles and the format of the discussion guide was based on the method by George et al (George et al., 2003; Krueger, 2006). Each session began with an introduction of the purpose of the session by the moderator. After that, the participants and researchers introduced themselves by first names.

The focus group discussions were divided into two main parts. The first half of the discussion concentrated on the parents' and patients' experiences with asthma, from the time of initial symptom presentation to diagnosis, and their coping strategies in terms of reactions and information seeking behaviours. The second half of the discussion concentrated mainly on the treatment if asthma; their perceptions of the medication and their coping or management strategies.

A combination of semi-structured and open-ended questions was used to guide the discussion. The structure of the questions were adapted from George et al, a focus

group study among African Americans (George et al., 2003). The specific items were determined and short listed from literature review of important aspects affecting asthma management, discussions with clinicians who manage asthma patients on a daily basis, and feedback from the interviewers who conducted the public perception survey (Chan & DeBruyne, 2000; George et al., 2003; Kieckhefer et al., 2000; Lim et al., 1996; Mansour et al., 2000; Osman, 1997; Peterson-Sweeney et al., 2003; Valerio et al., 2006; Van Sickle et al., 2001).

The questions had been tested in a mini focus group with 3 pharmacy undergraduates from the National University of Singapore who had asthma, and during a meeting with asthma nurses from KKH. The discussion guide was structured such that questions which potentially require patients to talk about these issues were preceded by a statement about how common the behaviour or belief was. This approach helped to "allow" patients to discuss certain "non-compliant" behaviours and views, which might be otherwise left out for fear of offending the investigators (Personal communication with Dr. Maureen George from University of Pennsylvania, USA). For example the question regarding compliance with daily medication was posed in this manner:

(Statement) *"Some asthma medications, for example, the inhaled steroids need to be taken everyday, and most people do not like to take medicine everyday".*

(Question) *"How do you feel about having to take medications daily? Do you stop taking them sometimes?"*

Each focus group session had between 4 to 7 patients. The sizes of the groups were kept small to allow each participant ample opportunities to share their experiences while maintaining a diversity of opinions.

Four languages had been used across the sessions. In order to reduce bias, all sessions for participants who spoke predominantly English at home were led by the same moderator (LY Chong). Similar approach was used for sessions conducted in the participants' mother tongues, except that the moderators of the same ethic group as the target participants and fluent in the mother tongues would lead the discussion, assisted by a co-moderator (LY Chong).

Before each session, all participants were briefed about the project. To encourage interactions among participants during focus group session, lunch boxes were provided, and participants were given a chance to interact with each other before each session. The investigators or the asthma resource nurses emphasized that participation was voluntary and the session would be audio and video recorded for analysis purposes. Demographic characteristics were collected after the participants agreed to the research and signed the consent form. The focus group sessions took between 2 to 2.5 hours, with a 15 minute toilet and tea break in between. All participants were provided with a transportation reimbursement of S$20. A nurse was in charge in child minding for parents who needed to bring along their children.

Table 3.1: Focus group discussion script

Section 1: Asthma perceptions, information sources and coping methods

1. When did you discover that you or your child has asthma?

2. Asthma is not very easily diagnosed sometimes, and some people took some time before they got properly diagnosed. How did you find out that you or your child has asthma?
   If participants mentioned that the doctor did not tell them they had "asthma"; this question will be asked: "Your doctor did not mention "asthma"? What terms did he or she use?" or "What did he or she tell you?"

3. Different people may react differently when they find out they have asthma. How did you feel when you were told by your doctor that you had asthma?

4. Friends and family are very important. How did your family members and friends react when they found out you have asthma?

5. People tend to offer many well meaning advice or suggestions. What are the suggestions or advices you have received?

6. Different people could be telling you to do different things about how to deal with asthma. Whose advice influenced you most?

7. Is there anything which we should have discussed, but we haven't?

Table 3.1: Focus group discussion script (Continued)

Section 2: Asthma management, medications and information needs

1. (Pointing or holding some inhalers) Most asthma medications come in the form of inhalers. How do you feel about using these puffers or inhalers?

2. Some asthma medications, for example, the inhaled steroids need to be taken everyday, and most people do not like to take medicine everyday. How do you feel about having to take medications daily? Do you stop taking them sometimes?

3. What are your concerns about using asthma medications?

4. We need to understand asthma well to take care of ourselves better. What information will be very useful to help to take care of yourselves better?

5. Most people still do not know much about asthma. If someone were to ask you, tell me "what is asthma", what would you say?

6. Do you have any suggestions or ideas on what could be done to improve how we treat asthma?

7. Is there anything which we should have discussed, but we haven't?

3.2.4 Data analysis

Focus group sessions were recorded, transcribed verbatim, and translated into English where necessary prior to coding. These translations were checked by independent translators, or the moderator (LY Chong) against the recordings to ensure the accuracy of translations.

Transcripts and field notes were systematically read line by line, coded and sorted for emerging themes, according to principles of content analysis (Weber RP, 1990; Rice PL et al., 1999). Similar responses were grouped together with code words to form thematic categories. Transcripts were analysed based on the key elements of content analysis with the assistance of the qualitative software ALTAS/ti5.2 (Scientific Software Development, Berlin, Germany) (Weitzman E & Miles M, 1995).

3.3 RESULTS

3.3.1 Patient characteristics

In total, 38 participants turned up to attend the focus groups. However, one participant who had followed her friends to the Malay language focus group did not meet the inclusion criteria. Another participant, a father of a teenage boy with asthma, offered to come for English language session. However, he did not seem to be able to converse in English, or understand the ongoing discussions. He was excluded in the analysis of the focus group.

Therefore, there were 36 eligible participants, who took part in one of the 7 focus group sessions conducted from March to May, 2004. Of the focus groups conducted, one was a multiethnic group session which was conducted in English, 3 were single ethnicity

groups (one Chinese, Malay and Indian group each) conducted in English, and another 3 groups (one Chinese, Malay and Indian group each) conducted in Mandarin, Malay and Tamil respectively.

The median number of subject per group was 5 (range: 4 to 7). The participant's demography is as shown in Table 3.2.

Table 3.2: Demographics and characteristics of participating parents and asthma patients

Number of participants (N=36)	n	(%)
Roles in the management of asthma		
Mother	23	63.9
Father	1	2.8
Patient	9	25.0
Parents who are asthma patients themselves	3	8.3
Ethnicity		
Chinese	12	33.3
Malay	12	33.3
Indian/Sikh	11	30.6
Others	1	2.8
Usual site of asthma care		
Restructured hospitals-respiratory specialist	11	30.6
Singapore National Asthma Program (SNAP)	16	44.4
Polyclinics	3	8.3
Private GP	3	8.3
Private paediatrician	1	2.8
KKH-non specialist	1	2.8
KKH asthma program + private paediatrician	1	2.8
Occupations		
Housewife	13	36.1
Healthcare workers	7	19.4
Administrative and clerical	4	11.1
Students	4	11.1
Others	8	22.2
Monthly Household Income		
<SGD 1000	5	13.9
SGD 1000-1999	5	13.9
SGD 2000-2999	11	30.6
SGD 3000-3999	6	16.7
SGD 4000-4999	5	13.9
>SDG 5000	4	11.1
Type of dwelling		
HDB:1-3-room	6	16.7
HBD:4-room	10	27.8
HDB:5-room& executive	16	44.4
Condominiums	4	11.1

GP= General practitioner, KKH= Kandang Kerbau Hospital, SNAP=Singapore National Asthma Program, a national program for high-risk asthma patients where newer, non-formulary asthma drugs were given 50% subsidy from the government, and asthma education were made available through asthma nurses. Polyclinics =subsidized government primary care clinics.

HDB=Housing Development Board, the administrative body that carries out a major housing project by the government of Singapore to provide affordable dwellings. Around 4/5 of Singapore residents live in these public housing flats.

3.3.2 General themes identified across all focus groups

The analysis of the study showed that there are predominantly 4 domains which were discussed across all the focus group. Each of this aspect had 3 to 4 "general themes" appear consistently across all focus group sessions. The domains and general themes are indicated in Table 3.3.

Table 3.3: General themes identified across all focus groups

A) Perceptions About Asthma

Food plays an important role in the cause, control and treatment of asthma
The mother is the central figure of managing a child or a teenager's asthma
An asthma attack is an emergency, and a traumatic experience

B) Management and Coping Strategies

Identifying and avoiding "triggers" through restrictions
Identifying, assessing symptoms and taking appropriate actions
Asthma control and symptom relief through "western" medications
Use of food, complementary and alternative treatments, and traditional methods

C) Barriers of Optimal Management Of Asthma

Suboptimal care and management provided by primary healthcare providers
Knowledge and attitudes about asthma
Beliefs and attitudes about long-term use of medication and inhalers
Getting the support to implement management plans

D) Wish List

1. Information needs
2. Removal of barriers in the healthcare system
3. Schools play a more supportive role

3.3.2.1 Perceptions About Asthma

3.3.2.1.1 Food play an important role in the cause, control and treatment of asthma

Throughout all stages of the discussions across all focus groups, each topic will be linked to food in one way or another showing that food plays a very central role in the mind of patients and parents.

This would be in line with the Eastern concept of maintaining a "balance" in the body for optimal health being widely held among parents and participants. Both the Ayurvedic and Chinese concept of health has similar concepts of "yin" (cool) and "yang" (heat). The Malays' traditional medicine, *jamu* also based a person's health on balance of heat and cold generated. The relationships of food to asthma are usually explained in the context of either "too heaty"or "cooling", and hence upsetting the balance.

It was commonly believed that the development of asthma is linked to taking certain food, whether by the mother of the child during her pregnancy, or by the patients themselves. In across the focus groups, food that were taught to have caused the asthma in the unborn children are generally "cooling" food like soy bean milk (drank in the morning), bananas, bird nest soup, mango, tea, etc.

The following are exchanges of 3 Chinese mothers from the Mandarin speaking session about eating bananas in pregnancy recorded and translated *ad verbatim:*

> **Mother 1:** When a woman is pregnant, can she eat certain things? You know, certain things are considered "cooling" and old people would say, "This one cannot eat", and "That one cannot eat"? If not, your child will have lots of phlegm. Because when I was pregnant, to tell you the truth, I actually took the banana. I did not know then. Then there was an auntie who saw me (taking it) and said "Who asked you to eat this? You cannot eat this!"
>
> **Mother 2:** You cannot. I have eaten one before, and I could not take it.
>
> **Mother 3:** Too cooling.

If the balance between "yin" and "yang" was lost through the consumption of an "unsuitable" food which is described in local terms as either too "heaty" or too "cool" for the person, it might also cause a person to develop asthma. For example, a Chinese mother from the Mandarin speaking group, who had thought that she caused her child to have asthma by being a "bad mother", said this:

> She was hit with this asthma, since small, when was a baby. I let her ate anything then. At first I put (her on) a milk powder, and the milk powder was not suitable for her. Too heaty, she had difficulty passing motion, so it she kept on getting breathless…

A Malay mother from the Malay language session said: "…they say it (asthma) is common, common among children, maybe because of things that they eat …."

Among the participants, food also seemed to the one of the most important factors to "prevent" asthma. To control asthma, they believed that many types of food should be avoided. There were some foods which commonly appear in the "forbidden"

list. Consumption of these food could provoke an attack, whether immediately or a few hours later, and could last for days. The commonly cited forbidden foods include chicken (causes phlegm), cold drinks (especially fruit juices), ice-cream, watermelon, oranges, and salted vegetables. These foods were thought to be too "cooling". Chocolates were also forbidden because it is "too heaty".

For treatment of asthma, and restoration of good health, food again plays an important role as well. Mothers would cook foods which are believed to correct the "yin" and "yang" balance, nutritious or recommended as a cure for asthma. This would be presented in more details in the section discussing the use of complementary medicines.

3.3.2.1.2 The mother is the central figure of managing a child or a teenager's asthma, and determining access to care

From the discussions of the focus groups, the mother plays a central role in the management of a child, or even a teenager's asthma. Mothers are usually the person who would recognise early symptoms of asthma, and decide which action to take. Mothers would learn through trial and error to accumulate experience to monitor a child's asthma symptoms, initiate treatment or seek help.

When a child is newly diagnosed with asthma, the mother has to cope with her own sense of guilt or blame by others, goes through the pain of seeing her child sick, on top of learning a lot of new information about to manage her child's asthma. She is also the frequent target of "advices" and "suggestions" from their elderly folks at home, relatives and friends. She has to incorporate and synthesize all these information, and is usually the main decision makers about the course of action to take.

For working mothers, they will depend on others to care for her child while she is at work. She would have to teach others how to use the inhalers, convince them to use it, and ensure that the dose and drug will be given when she is not around.

Mothers monitor their children to ensure compliance of medicines and also restrictions imposed. Mothers in this study reported high levels of self-efficacy, i.e. they monitored their child closely, "know what is going on" and would know what are the appropriate actions to take. . She is the main decision maker in the family on when and where to seek emergency treatment.

An Indian mother from the Tamil speaking group with teenage daughters explained why mothers need to pay close attention to the children:

> …So we also have to look after them, what they are eating. We have to tell them, "If you eat this, you can get (the asthma attacks) very fast". We have to tell them all the time.. We also have to take care of them. I cannot simply leave them, "What you want to eat, you eat", because they are the ones who are going to suffer. This asthma will mostly attack only at night …

Another Indian mother from the Tamil speaking believed that as mothers, they know their children very well, and could decide which are the appropriate actions to take are: "I think as the mother, I mean as the parent, we have to be able to detect when the child is not feeling well and all that…"

Since the burden of care falls mostly on the mothers, it is not surprising that 5 out of the 13 homemakers (38%) had mentioned in the focus group that they left their jobs because of their children's asthma.

3.3.2.1.3 An asthma attack, is an emergency, and a traumatic experience

Among the participants, asthma attacks were perceived as real emergencies, requiring prompt actions as a life could be at risk. Many parents would recall vividly; the time circumstances and triggers of their children's attacks. They described a lot of "suffering", "pain" on the children's part. They were "scared", "worried", and would "cry".

A young Indian mother from the Tamil speaking group recounted the night her son was admitted to the hospital:

> …my son just started to learn how to talk. He was two plus and we never heard him said "pain", until that night, when he was admitted to KK. He started to say, "Mummy, pain! Pain, mummy. Stomach pain, mummy. Mummy, here pain, mummy." And then all of a sudden, I was like…., for a moment I was like excited, he said this new word, "pain". Then I just felt very, very… (sighed).I almost wanted to cry. It was something new, but he was really like suffering. And he continued saying that, all the way until I was at the hospital. He kept saying "Pain! Pain, daddy, pain! Mummy, pain." I don't want to go through this anymore.

Another mother from the Mandarin speaking group decided to quit her job after her children's asthma attacks. She recounted what her experience when they were initially diagnosed, and admitted to the hospital:

> …because I was so lost, sometimes I cried. Initially, when they were admitted (to the hospital), it was two of them together. Both of them together, you know? You just imagine…When they are sick, we can't sleep, we are so worried, you know?

A Chinese teenage asthma patient who attended the English speaking group summed up the feelings about the urgency of getting immediate treatment for asthma attacks:"

3.3.2.2 Management and Coping Strategies

3.3.2.2.1 Identifying and avoiding "triggers" through restrictions

The main coping strategies of patient and parents were identifying food or circumstances which would provoke an asthma attack. Nevertheless, they obtained information about potential "triggers" mostly from family and friends instead of health care professionals (Table 3.4).

While most participants understood that "each patient is different", many commented that doctors did not give them specific list of things to avoid, particularly what food to avoid. This did not help them to manage asthma. Instead they relied on information from people around them, especially the elderly and other asthma patients, and the "sinseh" (the local term for traditional Chinese medicine practitioners).

The "triggers" which parents and patients thought affect them "personally" were frequently various types of food and drinks, flu, over-exertion and emotions. In contrast, tobacco smoke was mentioned by very few parents and patients. Only one parent thinks that her child is allergic to animal furs (carpets), and need to avoid "rolling around" on the carpets at home. Environmental control measures like frequent cleaning,

changing the bedroom's furnishings into dust-mite proof materials were only mentioned by a few mothers.

The most common strategy of trigger avoidance was avoiding or limiting intake of food as advised by others. As they get more used to living with asthma and gain more confidence, they begin to try some of the "things" in moderation, "just to see what happens". This usually happened when the patient or the child cannot resist the temptation of eating one of their favourite foods, or drinking cold drinks (which ranks very highly in the "forbidden list") in the hot weather of Singapore. A contact with a doctor who told them "everything also can eat" would boost their confidence to try for themselves.

Trying something on the forbidden list could have two consequences. "Nothing happened" or they "suffered" the consequences which they have been warned; a cough or wheeze which would start almost immediately or at night, or a worsening of cough due to production of more "phlegm".

If "nothing happened", they would try that particular food or drink a few more times, and monitor the outcomes. After a few trials, they would draw the conclusions of "That does not affect me". They will no longer consider that particular food as a "trigger", but that does not mean that they will openly consume that food. People around them, especially parents, may not be convinced that they could take the food without worsening their asthma. Teenagers would choose to consume the food "behind their back", to prevent naggings.

On the other hand, if they observed that they get attacks, or their symptoms worsened after taking a certain food or drink, this would reinforce their beliefs that the particular food should be avoided. They may choose to exercise "moderation" and "self-control" when eating it, or "…eat first, suffer later…"

The psychological impact of these food limitations was discussed in one of the Mandarin speaking focus groups. A mother shared that once she decided to stop believing in all these "grandmother's tales" and allowed her children to eat anything, her young children were no longer affected by these "triggers". She believed that some these symptoms after eating the forbidden food were psychological. A teenager from that group also shared her experience:

> **Teenager:** Then, just like what they say, after you just eat a little bit, you would start to feel very uncomfortable…
>
> **Parent:** You have eaten something you are not supposed to eat sneakily, so you feel terrible…
>
> **Mod:** Do you feel that it is psychological?
>
> **Teenager:** I don't know whether this is psychological. I just felt that after I ate, it felt like it was going to start already (asthma attack).
>
> **Parent:** Would you feel scared? When you eat that thing? When you eat that thing, would you feel like very sacred, or something like that?
>
> **Teenager:** Yeah, I would.
>
> **Parent:**That is that kind of psychology I am talking about.

> **Teenager:** And after that….then after that my mum says, "I don't want to be bothered about you already". Then after that…not anymore…I don't feel it anymore…

Across all focus groups, parents also indirectly mentioned the impact of restrictions and asthma attacks on their children. Many parents told us that their children would comply with the restrictions, because they were scared. For example, a mother in the Mandarin speaking session shared that her four-year-old girl did not dare to eat the chocolates and cakes in her classmates' birthday celebrations in school:

> …You see, my daughter is still so young. (She said) "Mummy, I (am a) poor girl. Everything-I cannot eat". For example, everyone at school is celebrating a birthday, there is cake, chocolate cake, and she does not dare to eat. She, herself, does not dare to eat. "I will cough, I am scared", she said…

Through trial and error, and obtaining more information from doctors, the parents and patients would eventually gain more confidence and more "relaxed" in their restrictions. They begin to exercise "moderation" in their restrictions. As "everyone is different", they become less likely to be influenced by "advices" of other people to stop eating a certain food. Their number of items in their list of "forbidden food" gets smaller and they may also allow small quantities of the food still in their own "trigger list" to be taken in "moderation". A mother from the Mandarin speaking focus group who had two children with asthma said this:

…Initially I did. Quite protective. But subsequently, because in the hospital, I mean, you want her to recover, yet (she) cannot eat (many) things. But if everyday, she eats only plain porridge, how is she going to recover? So in the end, I let them eat everything. Sandwiches, whatever. Even sushi, whatever! I let them eat. No, no restrictions. I feel like, if I control, listen to the grandmother's tales, like everything also cannot eat, I find that I cannot find out about anything…And for me, my husband was also quite liberal. He said, "Never mind，let them eat. If not how are they going to recover?" So I let them eat all the things. It seems ok. And then, to confirm (that it is ok), because I trust doctors more, I asked the doctors every time, "What are the things they cannot eat?" "Everything also can eat", they said. So, I let them eat anything….

Table 3.4. Recommended things which need to be avoided (restriction) or exposed/consumed in small quantities (moderation) by asthma patients to avoid asthma vs. Triggers which had been linked to asthma attacks by parents, or the patients themselves

Food	Recommended / practiced	linked attack	Non-food	Recommended / practiced	linked attack
"Cooling" food			**Cold-temperature or weather**		
▪ Watermelon	2	2	▪ Cold places-e.g. air conditioned places and "Snow city"	7	1
▪ Bananas	5	2			
▪ Orange	9	4	▪ Cold weather or weather changes	13	7
▪ Chicken	7	1	▪ Keep warm, wear long sleeved clothes	2	0
▪ Grapes	2	2	▪ Sleeping in air-conditioned room	3	1
▪ Salted vegetable	1	1	**Infectious**		
Cold food (temperature)			▪ Sharing of food and utensils with others	2	0
▪ Ice-cream	15	3	▪ Attending childcare/nursery	4	2
▪ Cold drinks: fruit juices, carbonated drinks, or plain cold water	24	6	▪ Going to the play ground	1	0
			Stress		
"Heaty" food			▪ Emotional stress	9	9
▪ Mangoes	2	0	▪ Over-exertion, including "play", and exercise	12	10
▪ Chocolates	6	5			
▪ Mandarin orange	3	2			
Others:			**Others:**	8	7
▪ Sour taste, acidic, Ribena ™, a black currant drink	3	3	▪ Tobacco smoke	7	1
			▪ Soft toys, carpets	3	1
▪ Sweets	4	1	▪ Pets	5	0
▪ Food colourings and preservatives	2	1	▪ Bathing at night, too early in the morning		

3.3.2.2.2 Identifying, assessing symptoms and taking appropriate actions

A key management strategy parents and patients take to manage asthma was learning to identify early symptoms of asthma and take actions as soon as possible to prevent worsening of symptoms. This management skill is acquired mostly through "experience", and supported by information obtained from doctors and nurses or through reading up. Once early signs and symptoms of asthma appeared, parents would initiate treatment, and monitor their children carefully to see if the attack escalates. Besides pharmacological treatments, some parents would get the child to sit up or lie sideways to ease the cough and offered hot drinks.

Parents and patients also learned how to differentiate between milder and more severe attacks by monitoring the symptoms, and comparing these to their previous experience. For parents of younger children, this would involve very close monitoring of the child, from the moment the child began to display symptoms such as cough or a runny nose. Parents generally believed that "they know their child" and could gauge the severity of an attack very well. For older children, the children will be consulted, and a joint decision will be made on whether to manage the asthma symptoms at home, go to a nearby clinic and get a nebuliser, or rush down to the hospital's emergency department.

3.3.2.2.3 Asthma control and symptom relief through "western" medications

Ventolin™ inhaler is the main means of managing the asthma symptoms and milder attacks at home, although cough syrup, Ventolin™ syrups or tablets may also be used

by patients who had not been prescribed an inhaler. Some parents and patients have also noticed that using a spacer would be more effective during attacks, and would use it instead of using the MDI directly.

In general, the Ventolin™ inhaler was viewed as providing fast, effective relief of asthma symptoms, and life saving. Even in the event of a severe attack which needed more intensive interventions like going to the emergency department, Ventolin™ inhalers helped to "buy time".

The Ventolin inhaler is also used in a "preventative" manner. It was used before exercises, and also before or after they consume a "forbidden" food or drinks. Patients, particularly children and teenagers thought that it could protect them from "triggers", and felt that it allowed them to "do whatever they wanted". "There is always Ventolin", in case "anything happens". Unfortunately, the salbutamol inhaler's efficacy has also caused ill-informed patients to use it daily as an "effective" preventer.

In general, only parents and patients who understood the role of preventers like inhaled corticosteroids (ICS) would view it as important, and tried to comply. Among these patients and parents, they found compliance, i.e. "sticking to schedule" tough when they started on the ICS. Most would eventually learn to manage it by incorporating it as part of their schedule, and keeping the inhalers in visible places like their bedside. A few female participants who had asthma would keep their inhalers in their handbags, so that they could use if they forget or have no time to use when rushing out to work.

Parents or patients who did not understand the role of ICS were resistant to its use as a long-term preventer, due the fear of side-effects, the perception that it did not work, or the hassles of daily use.

3.3.2.2.4 Use of food, complementary and alternative treatments (including "traditional" methods)

Many participants used both conventional medicine and CAM to manage asthma. Food was also believed to play a main role to prevent symptoms and restore health. The use of these alternative methods was mostly based on tradition, and the types of methods used differed slightly between various ethnicities. The general attitude of trying these methods was, "Who knows? It may work. No harm trying."

Generally, various types of herbs were widely used among participants across all focus groups, but the use was particularly high in the Tamil-speaking and Mandarin-speaking groups. Herbs based on traditional Chinese medicine (TCM), were most popular, followed by Ayurvedic herbalism. Herbs were popular because they are perceived to be "natural", and its safety and efficacy have been indirectly proven by hundreds and thousands years of usage.

TCM was used by parents and patients of all ethnicities, and some had also seen sinsehs on top of obtaining the herbs from the traditional Chinese medicinal halls in Singapore.[1] An Indian parent who was a nurse claimed a sinseh cured her son, a

[1] In Singapore, TCM are used or practised 2 on levels. There are many traditional "Chinese medicine halls" which are essentially shops selling a variety of herbs, prepared products and proprietary Chinese medicines over the counter. It is similar to a western pharmacy, but it is not necessary for shopkeepers or any staff to have any formal training or qualifications to set up such a shop. This is where most people would obtain their herbs and "Chinese medicine", and advice on how to use it. Other than these shops,

Malay patient said that she would continue seeing a sinseh, whose herbs seemed to help her if she could afford the fees, and another Malay patient who is also a mother of a young child with asthma said that she followed a sinseh's advice of avoiding chickens whenever she coughed, and it seemed to work. Other than seeing a sinseh, Chinese parents also purchased proprietary medicines like "*Hou Zhao San*" (literally translated as "monkey's claw powder", some kind of powdered herbs) to alleviate cough and "disperse" phlegm. Even Malay patients would buy popular products for cough like "Pi Pa Kao" (a type of cough syrup available from herbal halls or traditional medicine stores in Singapore).

The popularity of TCM is attributed to a more holistic approach of treating the disease, lasting effects, and safety. Parents and patients also said that the sinseh would tell them specifically what food to avoid, what to do and what not to do (like keeping warm); these were considered as important information which they perceive as not provided by western trained doctors.

"Food" and herbs are frequently combined to treat asthma by parents. Crocodile meat had been used by 10 participants (27.8%, 6 Chinese, 4 Indians) to "cure" asthma. The usual source of crocodile meat was the Chinese medicine halls, or friends who had purchased it for them. It was usually cooked as a soup with Chinese herbs. Indian participants also reported cooking it with other herbs, "the Indian way".

patients may see a qualified TCM practitioner, commonly referred to "sinseh" to get a diagnosis and a prescription of herbs. On top of prescribing herbs and or other proprietary Chinese medicines, the sinseh may also employ other methods such as acupuncture, tuina or moxibustion to treat the patients.

Other than "treating", herbs were also added into food to balance "yin" and "yang" or act as a tonic. These "tonics" and also other supplements like cod liver's oil, vitamin C and garlic pills were considered as very important to help the body build its natural "resistance", and counter the side-effects of the "strong" Western medications. Western medications are generally viewed as "strong", but would upset the body's balance and weaken a person if used for the long term.

All 5 Chinese mothers in the focus groups (both Mandarin and English speaking) have given *Cordyceps sinensis* to their children to help with asthma. This Chinese herb was usually cooked with lean pork, and taken as a soup during meals. Food with heating properties like "rasam[2]" and herbal teas made from mint leaves and other herbs, were also used by Indian parents on a similar principle.

There are also plenty of alternative and sometimes rather bizarre "cures" other than TCM and herbs. All the parents and patients had heard of eating bats as an effective way of curing the disease, and some had tried. Other "foods" which could cure asthma included white mice (to be swallowed alive), snake's gall bladder, iguana, "blue bird", pigeons, frogs, rabbits, camel's meat, insects and the faeces of "*belalang Mekkah*" (a type of large grasshopper).

Other non-"food" methods which were thought to help or cure asthma include reflexology, breathing exercises performed in meditations or yoga and swimming. A few Indian parents also used the "yoga method" of massages, and

[2] A type of South Indian soup. It is prepared mainly with the juices of tamarind and tomato with pepper and other spices. Lentils are added frequently and other vegetables optionally. It is eaten mixed with rice, or drunk by itself

"sucking out phlegm" the "traditional way"; methods which had been passed down from their mothers and grandmothers to clear phlegm and ease breathing.

In general, parents view CAM and alternative cures as "something which could be tried when the child is well", and not be administered when the child is having an attack. During attacks, using the Ventolin inhaler and going to the doctor is the best method, as these offers "fast relief", whereas the other methods "work slowly".

3.3.2.3 Barriers of Optimal Management Of Asthma

3.3.2.3.1 Suboptimal care and management provided by primary healthcare providers

Suboptimal care and management of asthma was widely brought up across all focus groups. In almost all groups, problems in the initial stages of asthma occurrence and diagnosis were common. In some situation, the problems persisted many years, resulting in negative outcomes like frequent A&E visits and hospital admissions, side-effects and poor quality of life.

A very common problem was delayed diagnosis of asthma. Patients recounted conflicting and confusing diagnosis, and it took some time, and usually takes a very bad attack requiring hospitalisation or A&E visit before being told that they or their child had asthma. This happened even to patients who had been following up with GPs or paediatricians closely.

Patients who had been symptomatic; like having recurrent, persistent cough, wheezing, and breathing problems were usually told that they had "bronchitis", "chest infections" or other terms instead of "asthma". To worsen the situation, different

doctors may tell them different things. The delay of diagnosis despite presentation of asthma symptoms delayed the implementation of proper pharmacological treatments, often resulting in severe attacks requiring A&E visit and hospitalisation. It also increased the denial and shock when parents or patients were told of the diagnosis, and prevented parents and patients to learn more about asthma to take the appropriate actions and precautions.

Suboptimal pharmacological management were very commonly reported in encounters with general practitioners in the private sectors and government polyclinics, both before and after the asthma diagnosis. Before asthma was diagnosed, patients depended on cough syrups like promethazine as the only prescription to treat their cough symptoms, and using the nebuliser at the clinics whenever their symptoms cause them to have breathing difficulties like wheezing. No inhalers would be prescribed, although quite a number recalled using Ventolin syrup or tablets which made them "shake".

Even when asthma had been diagnosed, many patients reported that the inhalers were not introduced in the GP or polyclinics. The use of cough syrups like promethazine still persisted, supplemented by Ventolin syrups, tablets and other unidentified "tablets". Ventolin inhalers and preventative medicines like ICS were usually only initiated in the hospitals after attacks requiring admissions. As a result of poor pharmacological management, patients reported side effects like "shaking" and "tremors".

3.3.2.3.2 Knowledge and attitudes about asthma

Across all groups, parents and patients consistently recounted how susceptible they were to try out "advices" from family, relatives and friends, and more vulnerable to "remarks" from other people when they were "new" to asthma. They tended to believe what others said, and this often resulted in a long list of "forbidden food", feeling "guilty" about "causing" the child to have asthma and pressurised to try various suggestions from people around them. Some of these suggestions on how to treat the asthma using alternative methods, could be expensive, detrimental, and most importantly, divert the patients, and the patients' resources away from complying with long-term use of preventers.

Lack of knowledge about signs and symptoms of asthma prevented some patients and parents from recognising that they might be having something more than the usual "cough" and "cold", and delayed them from seeking treatment or second opinions. Many parents and patients were "shocked" when asthma was diagnosed, despite having classic asthma symptoms for months, and maybe years.

For example, a 29-year Malay, female, university graduate recounted this:

> .... Actually I did not know I had asthma until I had breathlessness, and I went to the company doctor….(Before that, I had) a lot of wheezing and tightness of chest, but I did not connect that to asthma, because nobody in my family got asthma. So, when I went to the company doctor, they gave me nebuliser, and they send me to hospital. So, probably that was when it sank in. Because, I never thought that it was actually asthma…."

When diagnosed as having asthma, pre-existing beliefs and attitudes about asthma are important factors affecting the ability of patient, parents and their family members to accept the diagnosis, cope emotionally and move on to develop management and coping strategies. When parents or the patients are in a state of denial, they might not want to comply with the treatments prescribed. Misconceptions about asthma prevented many patients, parents and families from accepting the diagnosis.

There are many misconceptions about what it means to have asthma and the causes of asthma. The feeling of "guilt", "blame" and "why me" were common at the initial stages of diagnosis. Across all the focus group, only one parent had mentioned that asthma is due to the inflammation of the airways.

Asthma is still rather widely thought to be an infectious disease, as described by participants based on their own beliefs or their experience with people around them. This was more frequently experienced by participants from the Malay language focus group, and believed by participants from the Tamil language focus group.

This misconception became a barrier to optimal management of the disease in two ways. Firstly, people's reactions when witnessing an asthma attack or the use of an inhaler add to the barrier of using the inhaler when needed in school or in public.

For example, a Malay participant from the Malay language group explained the reluctance of using inhalers publicly: "…But people are afraid of it. So, when you get an attack, it's better to run. People are afraid that they could be infected with it.

Some say that asthma is infectious…"(Fatimah). A Chinese father from the English speaking focus group session, who had no asthma himself,

> …I believe that there people who are scared to take this type of medication in front of other people, because I had came across a girl who was asthmatic. My first impression was whether her asthma will spread to me…

Secondly, the concept increases the level of "dread" and of denial when asthma was diagnosed. It also causes patients to be treated differently by others. The belief that asthma could be "caught" somewhere, were expressed implicitly by parents of some groups. For example, an Indian mother from the English speaking group denied that there was a family history of asthma. She attributed her son's asthma to attending childcare:

> …actually, during my first pregnancy, I didn't have any problems. When my son was born, he was just normal. He didn't have any problem, until last year, (when) he went to childcare…
>
> … . And then, he recovers. After that, he gets back again because we still let him continue in child care, until in February. The GP advised us to withdraw him from childcare…

Two other Indian mothers, who were in another focus group (Tamil), said this:

> **Mother A:** Once she went for nursery, she mixed around, I saw, you know, I noticed, the cup and all that. I saw that. I noticed. The people there, *the cleaner,*

they never go and wash the cup properly with hot water. Just like that like that and she throw away. So, all the children went sick, you see? So, when she went for nursery, she gets this sick(ness). My other two girls, never! I never send them to nursery. So they start (with) K1. This younger (girl), because she was alone at home, the two sisters went to school, so I sent her to nursery. Then only she gets (asthma). The cups, all, were never washed properly. A lot of children get asthma, all complained to the…

Mother B: (interrupted mother A)….the hygiene!

A Chinese female teenager from the Mandarin speaking group recounted how she was prevented from sharing food with other children, "…My cousin's wife, she doesn't know about asthma, then she was like… what I drank, I cannot give to her children to drink…"

3.3.2.3.3 Beliefs and attitudes about use long-term use of medication and inhalers

Long-term, daily use of "medications" was not well accepted. According to the participants, the general perception of people around them was, "It is not normal to use medication everyday". Long term use was seen as "dependence" on medications, or even an "addiction". The body must "learn to build" its "resistance" or "immunity", and not "rely on medicines". This view was very strongly held across all focus group sessions, and was observed to influence compliance in two directions.

To the parents of young children who believed that children may have a better chance of "outgrow" asthma; this was a push factor to be compliant. They

adhered to the instructions to use preventers daily, with the hope that their children would get well as soon as possible, and not "having to depend on medications all their life".

To adult asthmatics and parents of older children who had taken medicine for years, it was an important reason of non-compliance. "For how long will I (or my child) need to depend on this?" This view is an important reason for patients to stop using the ICS on their own, sometimes just to see if they "really" still needed it.

The following is an example why a 19-year old patient in the focus group for English speaking Malays had tried stopping Seretide® (fluticasone propionate and salmeterol combination) even when he found it to be very effective. The "dependence" was even held by the mother of a young girl with asthma, who was a staff nurse:

> **Patient A**:…Like I wanted to try. Don't know. I just really wanted to try, just wanted to have a normal life like everybody. Like normal persons, (when they) go out, no need to bring Ventolin, or whatsoever…
>
> **Mother B:** Becoming too dependent.
>
> **Patient A**: Yeah, I just wanted to experience that kind of life, but it turned out that way….
>
> **Mod**: How about the others? How do you perceive a normal life? No medications?
>
> **Patient A:** Yeah, no medications.

> **Mother B:** It is not normal to take medications daily. I feel that when you are having a problem, you take medication only for a short period, and then you overcome it, and then it heals, it is cured. It should not be taking medications regularly, you see? It is not normal to have medications everyday. He (*referring to Patient A)* looks ok, but he still has to take the steroids, and all these, you see?...

Another example is from the English speaking groups for Chinese. A medical social worker with severe persistent asthma requiring frequent emergency department visits told us that she did not get the support from her parents:

> "My husband will also nag at me, that it is better to take the inhaler. But my parents are not very supportive. To them it is like if you are feeling better, then you are not supposed to take it so much. Don't keep relying on it"

For her, she still had the support of her husband, and many friends who are "respiratory doctors". These people would "nag" her about using her Symbicort® (budesonide and formoterol fumarate combination) inhaler daily, which was the opposite thing of what her parents wanted.

Usages of inhalers (any form, not just ICS) or spacer devices were viewed with scepticism or even rejected by the family and friends, especially the elderly. The main fears were dependence and even addiction. "Addiction and not just "dependence" were discussed among participants in the Malay speaking group. Perhaps surprisingly, the medical social worker was jokingly called a "drug addict" at work.

At home, the grandparents, especially the grandmothers were typically the main opponents, especially in the Indian families. Mothers felt pressurized to stop using the inhalers. In some instances, the rejection and reactions were strong enough to make young children scared, and refused using it. As there was already a strong view against the use of long-term medications, mothers had been influenced to discontinue by "people around them".

Here is an example of Indian mother from the English speaking group who had to "hide":

> …I am giving it daily, and I still feel very bad. Usually I will give in the room. I don't want to show to my in-laws. Actually I want to hide away from my in-laws, and others. Each time they see him do that, they will like, "Oh, so pity, so young". For them it is a big thing, you see? For them it is like, "Oh, putting a gas? Hah? So young!" …It really makes me feel like I was going to cry. So, now I have to bring him to the room…

Steroid inhalers were viewed even more negatively. There were a lot of misconception about steroids among patients, their family members and even members of the healthcare professional.

The combination of aversion to any use of long-term medications, and the specific fears about steroid inhalers which daily use of ICS in asthma, which is an "invisible" illness when the patient is not having an attack was particularly not acceptable.

Here is an example of why an Indian mother from the Tamil speaking group who stopped using the beclometasone dipropionate inhaler (Becotide®):

> …as what she said. That time when my children were first diagnosed as asthmatics, they were given the Ventolin™ and Becotide™. Along the way, people will always scare me, you know? "Oh this one you cannot take, if not forever in your life you will take…
>
> …This is nothing. This one Indian people will cure very fast. You can take this, you can take that….
>
> … but I think I am doing more care to my children, so I stopped giving according to the doctor's (advice). I never followed the doctor's advice. I stopped giving Becotide, when they are fine already, I stop the Becotide, just carry on with the Ventolin…
>
> …. People around me scared me, and then I stopped giving Becotide, because I thought Becotide is very high dose of steroid…

3.3.2.3.4 Getting the approval and support to implement management plans

Getting the support of others, especially family members in the management of asthma were important on two levels. Firstly, it is crucial for the actual implementation of the plans. Secondly, the "approval" or emotional support is important to preserve harmony in the family, or prevent exclusions socially.

The working mothers depend on other caregivers; usually the domestic helper, i.e., "maid" or other family members, usually the grandparents to help in the care of their children. The maids typically come from foreign countries, like Sri Lanka, Indonesia, and Philippines, and may face language and educational barriers in understanding the complicated treatment plans. A big proportion of grandparents found it difficult to accept that their young grandchildren had asthma, and opposed to the use of inhalers, particularly among Indian families. This was a practical barrier to many mothers, and they had to educate, negotiate and convince them of the importance of adhering to her plans. Mothers also had to teach these caregivers and ensure that they knew how to use the inhalers.

Other than the administration of medicine, to implement plans like "avoid tobacco smoke" was particularly challenging. Other than a few exceptions, most smokers (fathers, grandfathers) refused to quit. In this study participants reported that nagging the smokers to quit often resulted in "quarrels".

3.3.2.4 Wish List

3.3.2.4.1 Information needs

Parents and patients in these focus groups wished healthcare providers would provide more information to them about asthma, especially at the initial stages of diagnosis. Information which they wanted including "prevention measures", "more details" and "explanations" rather than general "layman" terms, and how to identify when to seek emergency help vs. managing at home. They also hoped that more information would be provided to the public, as this help to dispel misconceptions, and help other patients to identify asthma symptoms and come forward to seek help.

The most popular mode of education preferred by parents and patients were interactive sessions like counselling, where "you can ask questions", and because "not everyone reads". Other modes were talks, booklets and pamphlets. The mass media like television and newspapers were seen to be important in public education, and more information should be made available.

3.3.2.4.2 Removal of barriers in the healthcare system

One common grouse was the attitude of doctors, "…the doctors don't tell you much!" They wanted doctors to spend more time answering their concerns. They also thought that at times, they are not taken seriously at the emergency department when their children had attacks.

Mothers recounted experiences involving bringing the child to the emergency department when they thought the child was having a bad attack. After a few hours of waiting, the doctor would tell them that the child was alright and sent them home. This

could repeat a few times, where they brought the child to and fro between clinics and the emergency department, only to be told eventually that the child had a very severe attack, and needed hospitalization one to two days later. They hoped that doctors will consider their assessment of their own children, and the system generally be more supportive. As a mother from the Tamil focus group puts it: "Why can't they consider admitting him for observation? Why make me running here and there?".

Another important barrier that the participants hoped to be removed was the cost of care. Cost was an important consideration in choices of treatment, place of usual care and also compliance. Preventers, especially the newer preventers like Seretide® (fluticasone propionate and salmeterol combination) which were not on the formulary list were expensive to many participants in the long run. Patients in the Singapore National Asthma Program who had 50% subsidy on the price of the drug were thankful of the help. Some felt that the subsidy made it more "manageable" and "affordable", but wondered how others could cope. Even with these subsidies, participants had resorted to collecting their prescriptions in "instalments" instead of at "one-go" which could cost more than SGD200 for a 3-month supply. Two patients also rationed their inhalers and tried to "stretch it"; for example making a one month supply last two to three months.

Parents have hoped for more subsidies for the preventers, and help for families who are not able to afford. As one mother pointed out about the children; "…these are students…".

3.3.2.4.3 Schools play a more supportive role

In Singapore, the school environment is a major part of the children's life, and many children come from homes where both parents work full time. Parents in this study had expressed that they would prefer if the school system is more supportive and equipped to provide basic care to a child having asthma. Things on their wish list include provision of basic care like helping to administer the medications in younger children, or sending the child to hospital, as a child with an asthma attack "cannot wait". They also hoped that the role of the school dental nurse (as most schools in Singapore already have a dental nurse) can be expanded to provide basic care for children having an asthma attack, as asthma is "so common". Keeping a young child at home for many days causes child care arrangement problems. It was also a big hassle and very disruptive to their work to receive a call and "have to drop everything" and rush to the school the moment they receive a call that the child seemed unwell.

3.3.3 Cultural and sociodemographic differences

From the focus group discussions, there are obvious similarity and differences in the knowledge and belief about asthma among the different ethnic groups. Overall, the concept of "heaty" vs. "cooling" properties of various food was mentioned, believed and practised to various extents by participants from all groups. However, food as a trigger was discussed more frequently in the Tamil and Mandarin groups. Certain foods were only mentioned in one focus group but not another. For example, salted vegetable ("kiam chye" in local mandarin) was only mentioned by Chinese mothers in the Mandarin speaking group as being too "cooling" and a possible asthma trigger.

In terms of food as a cure, crocodile meat was mentioned in all groups. Each of the Mandarin, Malay and Tamil groups also mentioned specific alternative remedies not discussed elsewhere. The Mandarin speaking group mentioned a proprietary Chinese medicinal herb called "He Zhao San" (monkey's claw power) used to prevent cough and the Tamil group mentioned using iguanas and cooking crocodile meat with Ayurvedic herbs. The Malay language group mentioned insects like grasshoppers, rabbit's meat and camel's meat. Across all ethnicities, there was a trend that non-English speaking groups reported more experimentation with these "cures" compared to English speaking group. For example, 3 out of 5 parents in the Tamil speaking group had taken crocodile meat and another had tried "blue bird" whereas only one Indian participant from an English speaking session had given her son crocodile meat soup once when it was cooked and given to them by a friend. Half of the Mandarin speaking group had tried crocodile meat compared to only two of those who attended the English session. In contrast, Malay participants did not report using crocodile meat although they have heard about it.

Regarding social stigma, the Malay speaking group reported more examples of situations where people around them thought asthma was infections. In contrast, a few of the Indian mothers, especially the Tamil speaking group had indirectly attributed the start of asthma in their children with attendance in childcare or nursery implying that asthma being a contagious disease.

Worries about addiction were more common among Indians and Malays, who were more concerned about reliance or dependence on the medicine for long term.

The Indian mothers also seemed to have a stronger denial of asthma than others and faced more rejections about the usage of inhalers from the people around them.

3.3.4 Patient vs. parental point of views

From the discussions, parents were generally more worried about their children's asthma than the children themselves, whether the children were still young or already grown up. Furthermore, those parents in this study who had asthma themselves were more worried about their children's asthma than their own asthma. This observation is supported by the reports from the teenagers in this study that their parents were more concerned about their asthma that they did. Even the adult participants reported that their parents viewed their asthma more seriously and suggested restrictions which they did not think was necessary.

What was interesting was participants who had asthma placed more restrictions on their children than what they would practise themselves. They thought that they knew what they were doing, whereas the "children" (some would have already reached adulthood) did not. They worried about what the children ate in school, but thought that they were generally in control and would know whenever the children were unwell. The reports of the teenage participants in the study seemed to concur about not following restrictions on food or exercise "behind their parent's back". However, they knew what they were doing, and would use the Ventolin inhaler without letting their parents know when they had symptoms. Moreover, their parents did not find out about it most of the time. This is reported across all the three ethnic groups.

3.4 DISCUSSION

An important barrier to optimal asthma management discussed in this study is of great concern; the delay of diagnosis and suboptimal management in the primary care sector. The general practitioners act as the gate keeper in the healthcare system and play an important role in the management of chronic diseases such as asthma. A failure or delay to diagnose asthma and implement proper management is to putting the patient's well-being or life at risk, and could contribute to poor long-term outcomes like airway remodelling in uncontrolled and untreated asthma. For a disease that affects 1 in 5 children, and about 1 in 20 adults in Singapore, it also placed a costly and unnecessary burden to the healthcare system and the patients when the suboptimal management from primary care GP causes more patients to be hospitalized or seeking A & E attendance (Goh et al., 1996; Ng et al., 1994; Wang et al., 2004).

A study conducted among adult asthmatic patients who presented for acute asthma attacks in polyclinics showed that 14% were still using oral salbutamol, despite having asthma for nearly 20 years (Tan et al., 2000). In the current study which involved mostly parents of asthmatic children, the use of oral salbutamol and other cough syrup seemed to be even more prevalent, with the inhaler usually reported to be only introduced after an acute attack involving emergency department visits or hospitalisations. The observed preference of oral over inhaled route of administration caused patients to suffer unnecessary side effects like "shaking" and "tremors". This might play a role in patients fearing the side-effects of an even "stronger" medicine which could offer faster relief when introduced to the inhalers. As these are one-sided subjective reports of patients, it might be too early to draw conclusively that the general

practitioners had done a "bad job". A potential reason for their aversion is the time required to convince patients to use the inhaler and teaching them the proper technique. Further studies involving an audit or drug utilisation review would be useful to confirm this observation. In the mean time, more attention needs to be paid in educating general practitioners and equipping them with the skills to manage asthma, and overcoming the barriers to inhaler usage.

The worry about dependence and addictive properties of inhalers in general and specific concerns about steroid inhalers were common, and important barriers to compliance (Lim et al., 1996; Chan et al., 2000). In a public perception of asthma survey conducted in 2003, only 11% of members of the public did not think that long term inhaled steroid usage would not cause addiction (Chapter 4). Therefore almost every patient would have started with a negative view of steroid inhalers, particularly in long term use and in children.

Without proper education about the role and importance of steroids inhalers and information which specifically addressed their fears, it is unlikely that patients and parents would accept the usage in the first place. Complying with the medication for a long period of time is even more unlikely. With such negative perceptions of steroid inhalers, even parents who had intended to comply would be tempted to stop by the constant discouragement from people around them. Therefore, education should not be just "instructive", but aimed to equip the parents and patients with enough knowledge and confidence to explain and educate and gain the acceptance from people around them. This would be crucial for working mothers who need to gain the co-operation of their children's caregivers to give the children the medicines.

The mother plays a very important role in the management of children's asthma at home, and faces many challenges. Mothers have to learn to manage their children's asthma, besides dealing with their own distraught, family members who reject the diagnosis and people offering all sorts of advices and comments. The working mothers faced an extra layer in implementing the management plans as they depended on others to care for the child. The Asian culture emphasized strongly on filial piety. It would be difficult for the mothers to ignore or disobey to their own mothers' and in-laws' advices, let alone getting them to do something they disagreed to. As pointed out in this study, knowledge about asthma equips parents with the confidence needed to negotiate with others, and less susceptible to be influenced by the opinions of other people.

Therefore, a mother with a child who has asthma bears considerable emotional burden. They also take the main responsibilities of caring for the sick child. Therefore, healthcare providers may also want to pay attention to the emotional well being of the mother. In these situations, doctors and health care professional must also realise the importance of their role as the "arbitrator" in these differences of management. A few words from them to support the mothers' initiatives probably weigh more than hours of negotiation and explanations by the mothers.

This study showed that in the Asian society, social and family influences are very strong on the individual's decisions about their children or their own treatment. Grandparents, relatives, family and friends would influence a person's decisions and compliance. People care about how others see them. For example, to help patients from having to hide in the toilet to use their inhalers, the public need to be more aware about inhalers, and know that asthma is not a contagious disease. Therefore, public education

plays an important role. Without it, health care professionals will be in a constant tug of war with the negative views of the people around the patients to keep the patients compliant.

Among things on the wish list, parents in this study hoped for a more supportive school and childcare environment. This is not surprising as in Singapore; the school environment is a major part of the children's life (Wee et al., 2006). Keeping a child at home unnecessarily posed childcare problems and added to the stress of the child who missed school, and have to catch up. The cost of treatment is also an important concern that should not be ignored. In addition, the parents and patients in the focus groups also expressed that information about asthma should also be provided to them in a detailed and explanatory manner.

Some of the themes found in this study were similar the findings of other qualitative studies in asthma, especially at the macro themes level. For example, like the findings of Peterson-Sweeny et al, parents in both studies clearly wanted to be listened to, and acknowledged for how well they know their child (Peterson-Sweeney et al., 2003). They also expressed that from experience, they could identify whether their children were displaying signs of an asthma attack, and whether the attack is "different", or more severe from what the child had before. Parents in both studies also expressed confidence and the ability to control the medication utilization among younger children, but have less confidence about their school going children.

There are some important differences between the findings in this study and other qualitative studies conducted in Western countries. One notable difference is in

how asthma affected the patients' life, in terms of limitations and avoidance of triggers. The other difference is the notion that asthma is contagious.

Studies in Western countries more commonly list problems related to exercise limitations and environmental triggers like pollen and dust mites; food was almost never mentioned at all (Tumiel-Berhalter & Zayas, 2006; Cortes et al., 2004). The Singapore patients' limitations were mostly related to food, and this may not be totally baseless (Wilson et al., 1982). The importance of food was also congruent to another Singapore study about quality of life issues in children, where eating "healthy" food was important, and other reports about the role of food avoidance for asthma among Asian patients (Cane et al., 2001; Connett et al., 1994; Hazir et al., 2002b; Tam, 2002; Wee et al., 2006).

In this study, food was the main, and sometimes the only form of "triggers" which were thought need avoiding by participants. Therefore a major impact on patients' quality of life would probably be "can't eat what they want to eat", or "feeling different" in social situations because of the need to avoid certain food. This is an important observation, and would influence the relevance and accuracy of quality of life instruments in assessing the impact of asthma in countries and cultures which share similar concerns about food.

As far as we know, this is the first and only focus group study exploring the concept of asthma and its management of people from Chinese and Malay origins. Among people from South Indian origins, only one other study involving a group of mothers of Bangladeshi origins in UK had been reported (Cane et al., 2001). The mothers in that focus group also reported food restrictions as way to control asthma.

Like the Chinese participants in this study, they associated bananas with phlegm formation, although the author did not report whether this was believed to be due to the "cooling" properties of bananas, and or some other reasons.

Other studies involving Asian patients were conducted in the form of surveys. In Pakistan, a study involving parents of asthmatic patients reported that 89% would withhold certain food from the children, a practice called *parhaiz* (Hazir et al., 2002c). About two third of these respondents thought that *parhaiz* was an effective method in controlling asthma. In this group, food in the restricted list was various types of rice, oily food and certain drinks.

In our study, some participants, especially in the Tamil focus group seemed to believe that asthma is contagious. Others, especially the Malay focus group members, reported that some other people around them thought it is. This "contagious" concept may not be only limited to Singapore. In the Pakistani survey, 1 in 3 of participants thought that asthma is contagious, some mothers in the UK study reported that other people around them thought so (Cane et al., 2001; Hazir et al., 2002d). Whether the misconception that asthma is contagious affects patients' quality of life or self-esteem in Eastern countries have yet to be studied. However, it would be obvious that there exists certain level of social pressure and stigma. Like food, these were not included in quality of life questionnaires for asthma, and caution could have to be exercised when adapting these instruments to Asia.

Therefore, the findings of this study are potentially applicable not only in Singapore, but may also be applicable in other Asian countries like India, China and Indonesia or Asian communities in other countries. Compared to many Asian countries,

Singapore, a city state where English is the *lingua franca* is considered "westernised". Yet, the traditional health beliefs still hold a strong place, and influenced the management of asthma to a great extent. In the countries where these concepts about "yin" and "yang", (where the concept of "heat and cool" originated from) still hold, similar or equivalent concerns about use of long-term "Western" medications, restrictions and limitations imposed on asthmatic patients and applications of traditional medicines may also exist.

CAMs were widely used among the participants. This is consistent with earlier studies which showed the widespread use of CAMs, including in (Morgan DL., 1988; Rice PL et al., 1999). About 1 in 4 respondents in a recent study would actually prefer its use over conventional western medicine for asthma (Lim et al., 2005). As reported by Ng et al, the CAMs most widely used were those which are "traditional", such as herbs, TCM or those more "bizarre" methods based on folklores about "cures" (Ng et al., 2003b). CAMs which were reported as popular in Western countries such as homeopathy and aromatherapy were not widely used (Slader et al., 2006). This is another example how differences in the views about health resulted in a difference in management in a Western country vs. an Asian country.

The strength of qualitative studies lies in its relevance to the topics explored, and not the generalisability of the study (Giacomini & Cook, 2000). This study had obtained relevant information which is important to health care professionals who deals with patients and also policy makers. The inclusion of patients from all walks of life and three major ethic groups adds to its importance.

To minimise the problems of generalisability of findings which is often cited as a main problem in qualitative research, we aimed to include a heterogeneous sample of participants as far as possible. Participants were recruited from various places of usual care. Patients from private and public specialist clinics, government polyclinics and general practices were included in the study. Various levels of asthma severity and control, educational and income levels, age and occupations were also represented. However, the recruitment of patients through hospital and clinic settings had inevitability attracted the attention of asthmatic patients or parents of asthmatic children who worked in these settings. They came forward to volunteer for the studies and as a result, we had seven healthcare workers participating in the study i.e., two clinic assistants, three nurses (from different hospitals), one social worker and one psychologist. It would be difficult to ascertain whether the presence of these subjects would have affected the discussion. However, this problem would be at least ameliorated by our study design of using the same moderator with standardized training in the focus groups.

In addition to taking notes during the focus group session, video and audio recording were performed so that the sessions could be reanalysed as accurately and closely as possible. As opposed to using just audio taping like most reported focus group studies, the video recordings were important as Asian participants may not be as vocal in expressing their opinions, particularly disagreements. They might respond in a more passive manner. For example, we wanted to ensure that disagreements (which may not be expressed, since this were among “strangers”) or agreements to statements

by other participants which were expressed via body language like nodding the head (agreeing) or shaking the head (disagreeing) was reflected in the analysis.

Participants were grouped according to ethnicity based on the assumption that ethnicity is an important factor affecting asthma perception and coping strategies (Partridge, 2000) . Four main languages are spoken in Singapore, English, Mandarin, Malay, and Tamil. Although English is commonly spoken in Singapore, many people are still more comfortable in their own mother tongues, particularly among those who had lower educational levels. As such, participants were grouped according to their preferred languages. This would eliminate situations where groups may be dominated by participants from higher socio-economic groups, at the expense of the lower socio-economic group participants. Other than these practical reasons, this move was also supported by findings that other than ethnicity, the primary language used at home did influence the management and outcomes of Latino adolescents with asthma (Chan et al., 2005).

3.5 CONCLUSIONS

Findings from this study showed that there are still many barriers to optimal care of asthma. These barriers generally lie in the attitudes and beliefs about asthma and its medication and the healthcare system. What is notable and interesting was that almost all these barriers (except the cost of care, and support from the schools) could be considerably reduced with greater awareness about asthma among members of the public, healthcare professionals and the patients. Support from the schools, as we concluded from this study, seemed to vary as well. In rare cases, schools paid attention

to the needs of children with asthma, after some "experiences". Greater support from them might be possible, if the education system and teachers know more about asthma and understand the importance of their roles in childhood asthma.

Important differences in terms of towards food and asthma management in terms of balancing "yin" and "yang" compared to Western countries were also noted. These differences in views and management of asthma could impact patient compliance and quality of life issues. Hence, researchers and healthcare professionals need to exercise caution when adapting quality of life instruments or educational programme contents from the West, and take steps to ensure concerns specific to their target population were appropriately addressed.

In conclusion, asthma awareness is an important cornerstone in optimal patient management. Comprehensive education initiatives targeting the public, healthcare professionals and patients should be investigated as a tool for overall improvement.

3.6 ACKNOWLEDGEMENTS:

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Special thanks also to the asthma resource nurses from the Singapore National Asthma Program, especially the nurses from KKH's National Asthma Shared Care Programme (NASC); Sister Teo Ai Huay, SSN Zaliha Bte Yatim, SN Chua Lilian and SN Gan Wee Lin. The Tamil language session would have been impossible without the help from Miss Priya Appan who helped with the translation and moderating session.

Chapter 4. Public perception of asthma: popular beliefs and myths

4.1 INTRODUCTION

Effective self-management and medication plan adherence are critical factors in effective long-term outcomes and disease control for asthma (Bone, 1993; Clark et al., 1994). These are enhanced when treatment regimen and health advice is concordant with patient's health beliefs (Cooper et al., 2001; Lim et al., 1996). Patient education and counselling has been actively advocated and implemented to enhance these factors (Global Initiative for Asthma., 2002; MOH Clinical Practice Guidelines 1/2002: 2002). However, these programmes reported variable degrees of success in improving asthma related clinical outcomes, or in reducing emergency care and hospitalisations (Cooper et al., 2001).

These inconsistencies have been attributed to factors such as different content, purpose, target population and intensity of programmes or even reported ethnicity (Mitchell et al., 1986; Moudgil et al., 2000). It is recognised that good knowledge itself does not directly translate to positive attitude and behavioural changes (Gibson et al., 2002). Other intrapersonal factors such as feelings, health beliefs and attitude are also considered important (Clark et al., 1994). In turn, external factors and resources such as social support, and role models can affect these characteristics (Clark et al., 1994; Sin et al., 2005).

Information, which is inconsistent with a person's beliefs, may not be so easily accepted. For example, a study conducted in Singapore pointed found that certain knowledge or perception about asthma were more difficult to change after an intensive one-to-one counselling session, possibly due to strongly held health beliefs

related to the ethnic and cultural health beliefs and practices (Prabhakaran et al., 2006). In an Asian society such as Singapore, the perception of family, friends and other members of the society, which make up an individual's lay referral system, could strongly affect the beliefs and action of asthma patients. Increasing public awareness about asthma may contribute to a change in the overall health beliefs of the society. It could also help to reinforce patient-focused educational efforts and help the lay referral system to work more effectively in identifying children and patients with asthma that are not currently getting appropriate medical treatment.

To our best knowledge, there are no published large surveys of public perception of asthma, although studies on the public's beliefs, knowledge or attitudes of other diseases such as cancer, diabetes, dental diseases, AIDS and osteoporosis had been undertaken (Wee et al., 2002; Weintraub et al., 1985; El-Qaderi & Quteish, 2004; Quek & Li, 2002; Nyame & Biritwum, 1997; Saw et al., 2003). Apart from a pilot study conducted in Chicago, no major studies on the public perception of asthma has been published to date (Conway et al., 1999). Studies on asthma knowledge have so far been mostly conducted among on patients, the caregivers or members of the healthcare professionals (Chai et al., 2004; Chong et al., 2000; Hazir et al., 2002e; Lim et al., 1996; Shivbalan et al., 2005; Wong et al., 1994; Conway et al., 1999; Rubinfeld et al., 1988).Most large scale studies have been focused on asthma control and prevalence aspects (Zainudin et al., 2005; Neffen et al., 2005; Lai et al., 2003) .

A public survey, especially in a multicultural society in Singapore may also shed some more light to the observations of differences in asthma outcomes between

different ethnicities in a society. For example, Indians and Malays accounted for higher number of hospitalisations due to asthma than Chinese patients, and these observations have been well documented and reported (Ng & Tan, 1999; Ng et al., 2003a; Niti & Ng, 2003). However, there were no reported studies, other than anecdotal reports about the cultural influences on asthma perception and management in Singapore (Connett et al., 1994). This is an area worth investigations, as Malay patients also accounted for disproportionately large percentage of patients in high-risk asthma programs (Teo AH & Mohd Yatim Z, 2003). Beliefs about asthma and its management could differ between different countries and ethnicities due to cultural and traditional influences in health beliefs, and these could be factors which affect the health outcomes (Cane et al., 2001; Tam, 2002). If there are prevalent misconceptions about asthma, this could be barriers in adherence and seeking appropriate treatment. These misconceptions should be identified. Therefore a survey on the public's perception of asthma would provide important and useful information for both public and patient education purposes, and valuable insights about how socioeconomic differences are associated with these perceptions.

Our main aim was to understand the public's common perception and beliefs about asthma, in order to provide healthcare providers with information to devise effective and culturally sensitive plans. Understanding the problems from the layman's viewpoint helps the health care professionals to communicate more effectively and tailor individual patient education to specifically target and allay the misconceptions about asthma. Tailored, effective education had been shown to

compensate for the poor outcomes associated with patients' lower health literacy (Mancuso et al., 2006; Paasche-Orlow et al., 2005).

In this public survey, we also hope to test several hypotheses and common presumptions about the understanding of asthma in the layman. Firstly, we hypothesize that there may be differences on how asthma and its treatments are perceived among different ethnic groups both in terms of *level* (i.e. how much they know) of also the *type* (what kind of beliefs they held) of understanding due to cultural differences. Secondly, level of knowledge is likely to be associated with socioeconomic factors. Socioeconomic factors, in particular educational level, have been shown to be predictive of health literary and disease understanding, and these would be explored assumptions would be explored. We also hypothesize asthma patients should know more about asthma than those without asthma. The understanding about asthma could also be influenced by the sources of health information a person normally uses, and the influence of this factor were also tested.

We believe the findings of this study would contribute to the improved management of asthma in Singapore, and understanding about the cultural influences internationally. This information could contribute in formulating more focused and cost-effective public campaigns to target common misconceptions of asthma. These concerns also need to be tackled on the individual patient level. Without addressing these common concerns, patients might difficulty believing and accepting instructions and advice given by healthcare professionals which are not congruent with their own beliefs or the beliefs of influential figures in their lay referral system have different

opinions. These efforts are important, as asthma is a common chronic problem in Singapore, and is known to be under diagnosed and under treated (Lim, 2003). No efforts should be spared in improving access to care as proper treatment improves quality of life.

4.2 METHODS

4.2.1 Subject characteristics and study design

Ideally, a probability sampling method would have been ideal to collect a representative sample of members of the public, so that the results can be generalised, and representative of public view. However, due to the following reasons, we took a different approach:

1. Amount of funding available was about $3000
2. The objective of the study was to investigate whether socioeconomic factors, particularly culture & ethnicity contribute to differences in perspective. The percentage of Chinese, Malays, Indians and others were 76.8%, 13.9%, 7.9% and 1.4% respectively. In order to collect samples from the Malays and Indian populations, the total sample size would increase dramatically. This was unaffordable.

Therefore, pragmatic approaches was used in the sampling, with the objectives collecting enough information of from the minority groups, and increase the likelihood that subjects who are normally not included in “street surveys” are included.

The subjects were surveyed by approaching members of the public at two main types of public areas: (1) public areas that attract people from diverse socio-economic, age and ethnic groups, and (2) areas where people from socio-economic groups that were difficult to reach tend to visit. The public areas targeted were neighbourhood and downtown shopping centres, MRT (Mass Rapid Transit) stations and bus interchanges and open spaces in the heart of the central business districts of Singapore. The other areas are polyclinics and hospitals where the usually housebound and elderly could be reached; Geylang Serai, Little India and Chinatown which are popular among elderly people of Malay, Indian and Chinese origins; and mosques where the Muslim community could be reached in large numbers.

Members of the public would be approached randomly and the purpose of the study was explained to potential participants. Consenting member of the public aged 16 and above who were able to read or converse in English, Mandarin, Malay or Tamil were invited to complete the survey, and offered a choice of self-completion or interview as mode of completion. Participants who expressed preference of self-completion were given a survey form in their preferred language (English, Mandarin, Malay or Tamil) and would complete the survey under the supervision of the interviewer. The interviewer would offer assistance and clarification should the participant have any queries or express difficulty in understanding the questionnaire. For participants who preferred to be interviewed, the interviewer would read out the questions line by line, together with the answer choices.

Interviewers in this study were honours year pharmacy students and a medical undergraduate from the National University of Singapore who had been trained interview techniques and asthma knowledge. They were given a list of standard responses to the terms which may be asked by the public. For example, "wheezing" should be explained as "high pitched whistling sound when breathing" (a description which is observed to be commonly used by patients) and "triggers" should be explained as "things that could *'start'* (rather than *'cause'*) an attack in an asthmatic person" to avoid confusion. They were instructed not to provide any answers to the questions, until the participants have completed the whole survey.

4.2.2 Design of asthma perception questionnaire

The questionnaire was developed to capture information which was deemed either basic information which the public should be aware of, commonly misunderstood or important in the management of asthma. A list of questions was generated from patient information booklets, and other sources of information regarding asthma such as the Health Promotion Board's website and contributions from clinicians and asthma nurses. These were then short-listed based on the criteria stated, and modified accordingly based on feedback from the pre-field tests.

Questionnaires were translated in to Mandarin, Malay and Tamil versions. Both forward and backward translations involving translators from both medical and healthcare related background and non-medical or healthcare backgrounds were conducted to ensure conceptual equivalence, and that items would be interpreted

correctly by the layman. All questionnaires were piloted and modified as necessary before being used.

The questionnaire was designed with four sections.

- Section 1: Demographics
- Section 2: Perception of about pathophysiology, risk factors, symptoms, trigger factors and complications of asthma, and lifestyles of people with asthma. This section, which would be referred as "Asthma Perception" (AP) has 51 items.
- Section 3: Perceptions or knowledge of treatments and management of asthma. This section would be referred as "Asthma Treatment and Management" (ATM) section in this chapter and had 25 items.
- Section 4: Miscellaneous items such as awareness of resources and support group for asthma patients, beliefs about common alternative cures for asthma, perception about asthmatic women who are pregnant, beliefs about the important factors in asthma control and common sources of health information.

Sections 2 and 3 and 4 contain statements where respondents can choose "Agree"/"Disagree" or "Unsure" as options. For Sections 1 and 4, appropriate options such as Likert scale measures, "Yes" and "No" options were used as appropriate. For the section on beliefs towards asthma control *(e.g., In your opinion, how important are these factor(s) in controlling asthma?*) and sources of information (e.g., *What are your important sources of health information*), respondents were asked to rank each source of information in terms of their importance as a source of health information to them.

A 5-point scale was used in this section. The rating score was the following: 1 = not important at all, 2 = not important, 3 = quite important, 4 = important and 5 = very important.

4.2.3 Data checking and entry

Prior to data entry, all questionnaires were manually checked and coded. Questionnaires which had been marked as invalid or incomplete by the interviewers would be reviewed and removed as necessary based on observations of the interviewer and the trends of answer choices. Questionnaires with more than 10% of missing answers would be removed from the analysis. The responses were then coded independently, before being entered into an Excel spreadsheet (Microsoft Corporation, Redmond, Washington). Coding and data entry, and random checking of entered data were performed independently in 3 separate processes to minimise errors.

4.2.4 Statistical Analysis

Data were analyzed using both Excel (Microsoft Corporation, Redmond, Washington) and SPSS (SPSS Inc, Chicago, Illinois). To meet the objectives of the study, which was to obtain results which would be useful from at public health or education level and at the individual patient level, the analysis were designed in the following manner:

1. For ease of coding and analysis, answers which are consistent with evidence available are designated as “correct” and distinguished from “unsure” answers and “wrong” answers. Distinguishing these answers allow for different strategy to be applied in addressing the issues. Therefore,

scores for both "wrong" and "correct" answers were provided along with the "total score", which would be a useful indicator to monitor the overall knowledge.

2. The results were analysed on 2 levels: a section score level, which provided a summary score for each section of the questionnaire, and at the item level.

The Asthma Perception (AP) and Asthma Treatment and Management (ATM) sections were scored and totalled. The numbers of correct, unsure and wrong answers in each section were calculated. Then the values for AP and ATM were added up to

$$\textbf{Mean OAK} = \frac{\text{Mean score of AP} * 51 + \text{Mean score of ATM} * 25}{\text{Total number of items}}$$

Total number of items =76

give an Overall Asthma Knowledge (OAK) score.

The distribution characteristics of the scores were checked, and parametric or non-parametric tests were applied as appropriate. In general, $p \leq 0.05$ was considered statistically significant for all analyses, with the exception of item level analysis where $p \leq 0.01$ was applied.

At the section score level, socio-demographic variables that could affect the levels of knowledge or perception of asthma and its medication, beliefs about factors important to asthma control and sources of health information were analyzed using linear regression model, while at the item level, multinomial logistics regression

models were applied. Independent variables included in each model were education, age, family income, race, health related vs. non-health related occupations, occupation, knowing someone has asthma, respondent has asthma, close family members has asthma, relatives have asthma and colleagues or friends have asthma. The main sources of health information were also included in the models.

4.3 RESULTS

4.3.1 Subject characteristics and demographics

Members of the public were surveyed from various locations such as Mass Rapid Transit (MRT) stations, Housing Development Board (HDB) heartlands, Central Business District (CBD), polyclinics and Kandang Kerbau Hospital (KKH) at various times of the day. Ten interviewers consisting of final year students from the Department of Pharmacy and medical undergraduate conducted the surveys. The surveys were mostly self-administrated (62.6%) with assistance when necessary by interviewers (12.2%). 25.2% of the surveys were conducted through interviews, with interviewers reading out the questionnaires. The response rate was about 1 in every 2 persons approached.

In total, 1222 questionnaires were returned by the interviewers. After an initial quality check, 1143 questionnaires were entered into the spreadsheet, and 1113 valid cases were retained for analysis after removing incomplete or surveys which started to show signs of respondent burden such as consistently choosing the answers from the same column, or patterns of answering start to change at the later part of the

questionnaire. We had also removed surveys pointed out by interviewers to have been completed 'too fast' (less than 5 minutes) by respondents. 44% of respondents were male, 57.8% had up to secondary school education or ITE, 63% has a family income between SGD1000 to SGD5000, and 94.2% did not work in healthcare related industries. (Table 4.1 and Table 4.2)

Out of the 1113 valid cases, 62.4 % were self-administered, with 90.6% of self respondents choosing to use the English language questionnaire. Four percent of the self-administered questionnaires were Malay, 5.2% Chinese and one Tamil language respectively. The rest of the surveys were either fully interviewer administered or self-administered with assistance from the interviewer. (Table 4.3)

4.3.2 Overall performance for Asthma Perception (AP) and Asthma Treatment and Management (ATM) Sections

The Asthma Perception (AP) had 51 questions, while the Asthma Treatment and Management (ATM) had 25 questions. The distributions of the scores Management (ATM) and Overall Asthma Knowledge (OAK) are shown in Figure 4.1-Figure 4.3. The mean score of the AP section was significantly higher than the ATM section. (26.5% ± 10.6 vs. 24.2%±20.7, $p<0.001$, Wilcoxon Signed Ranks Test). Total score of these two sections was 25.7%±18.8. The Asthma Perception (AP) Section had significantly higher percentage of correct answers compared to the ATM (46.3% ± 19.3 vs.41.1%±21.0, $p<0.001$, Wilcoxon Signed Ranks Test). However, the

percentage of wrong answers were also higher (19.8% ± 10.3 vs. 16.9% ± 11.4, $p<0.001$, Wilcoxon Signed Ranks Test).

Table 4.1: Characteristics of respondents to the survey

	N	Percentage
Total number of valid cases	1113	100%
Gender		
Male	494	44.4%
Female	619	55.6%
Age (years)		
16-20	149	13.4%
21-30	308	27.7%
31-40	265	23.8%
41-50	181	16.3%
51-60	134	12.0%
>60	76	6.8%
Race		
Chinese	593	53.3%
Malay	279	25.1%
Indian	199	17.9%
Others	42	3.8%
Total	1113	100%
Education		
Some primary education	52	4.7%
Completed primary education	110	9.9%
Completed secondary education	406	36.5%
ITE	75	6.7%
Polytechnic/Pre-university/JC	226	20.3%
University/Post-graduate	219	19.7%
Not reported	25	2.2%
Occupation		
Non-healthcare related	1048	94.2%
Healthcare related	62	5.6%
Not reported	3	0.3%
Family Income		
No Income	83	7.5%
<S$1000	153	13.7%
S$1000-1999	252	22.6%
$2000-2999	243	21.8%
$3000-4999	212	19.0%
$5000-7999	93	8.4%
>$8000	69	6.2%
Not reported	8	0.7%
Know Someone With Asthma	685	61.5%
Respondent Has Asthma	104	9.3%
Family Members Has Asthma	228	20.5%
Relatives Has Asthma	187	16.8%
Colleagues/Friends/Classmates	318	28.6%

Table 4.2: Breakdown of occupational types of respondents

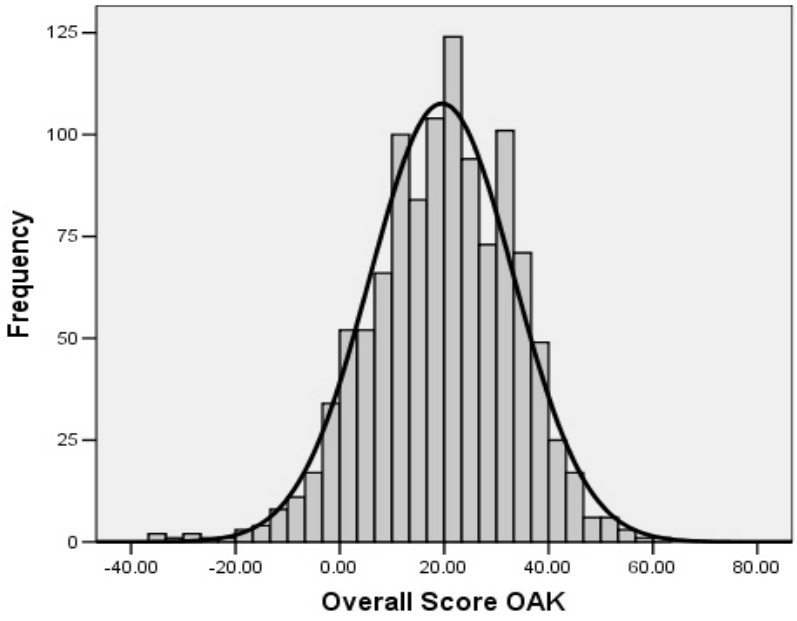
Occupation	N	Percentage
Doctor/Dentist	1	0.1%
Nurse	23	2.1%
Other Allied Healthcare Professionals	33	3.0%
Managerial/Professional	122	11.0%
Self-Employed	89	8.0%
Technical/Skilled Worker	173	15.5%
Clerical/Admin	152	13.7%
Housewife	160	14.4%
Student/Serving National Service	190	17.1%
Retiree	67	6.0%
Unemployed/In between jobs	45	4.0%
Others/Unskilled workers	29	2.6%
Not reported	33	2.9%

Table 4.3: Mode of administration and language used

	N	Percentage
Number of valid cases	1113	100%
Self administered	695	62.4
English	630	56.6
Chinese	28	2.5
Malay	36	3.2
Tamil	1	0.1
Assistance required*	135	12.1
English	108	9.7
Chinese	7	0.6
Malay	20	1.8
Tamil	0	0.0
Interviewed	283	25.4
English	197	17.7
Chinese	48	4.3
Malay	36	3.2
Tamil	2	0.2

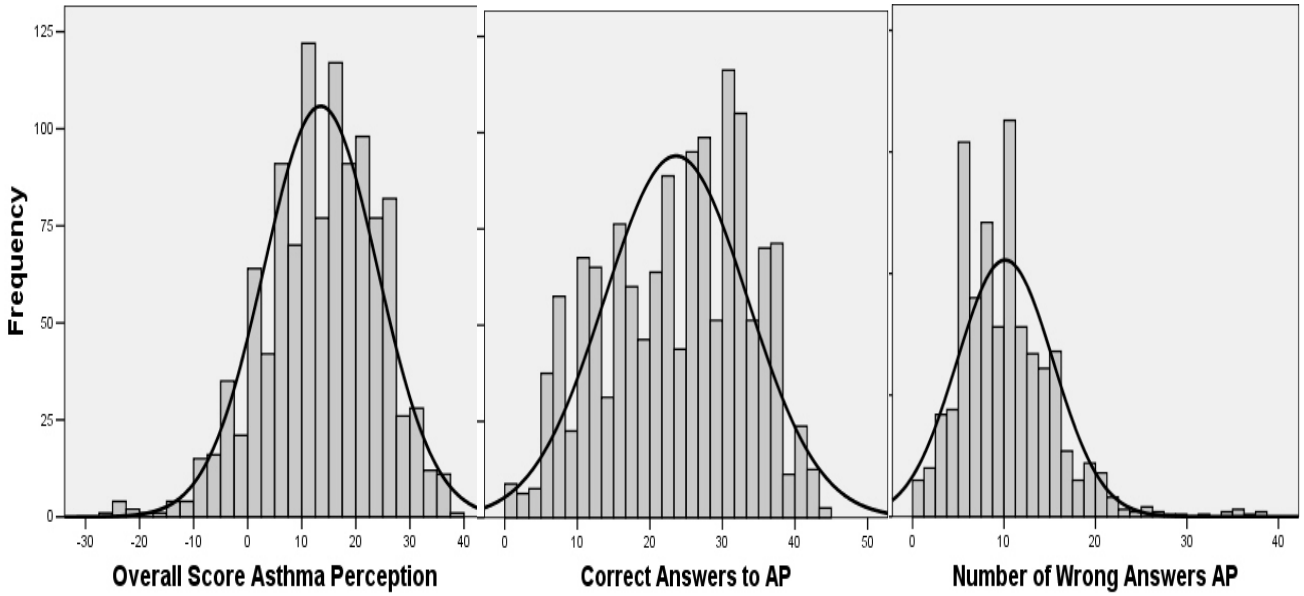
*In these cases, participants chose self administration, but required clarifications or the interviewer to read out more difficult words

Figure 4.1: Histogram of the OAK score (Overall Score)



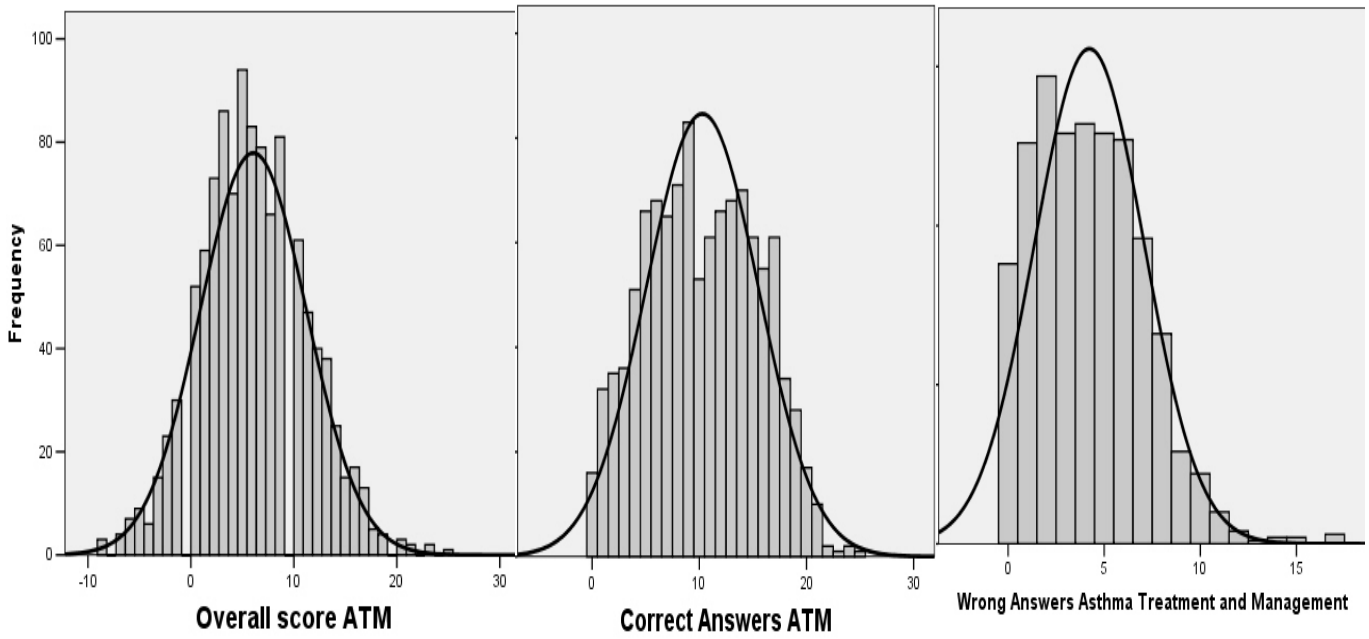
The Overall Asthma Knowledge score showed a normal distribution.

Figure 4.2: Histograms of the Asthma Perception section scores



The number of wrong answers in the Asthma Perception (AP) section was skewed to the left, while the overall score of asthma perception skewed to the right.

Figure 4.3 Histograms of the Asthma Treatment and Management Scores



The number of wrong answers in the Asthma Treatment and Management (ATM) section was skewed to the left, while the overall score of ATM skewed to the right.

Table 4.4: Scores of various sections in the survey

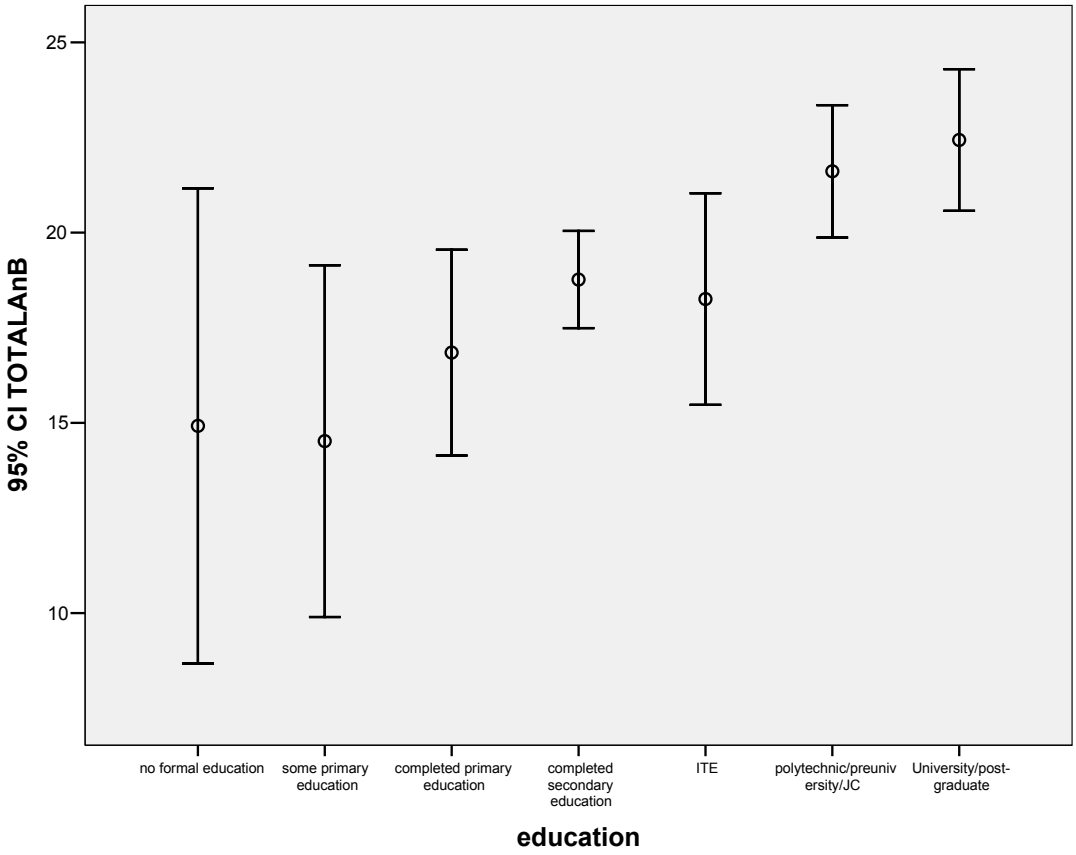
	AP[#] (51 items)		ATM[#] (25 items)		OAK (76 items)	
	Score	%		%		%
Overall scores*						
mean	13.5 ±10.5	26.5±10.6	6.1± 5.0	24.2±20.7	19.6±13.7	25.7±18.8
median	14	27	6	24.0	20	26
mode	18	35	5	20.0	19	25
range	65(-26 to 39)	127.5	34(-9 to 25)	136(-36 to 100)	97 (-35 to 62)	
Skewness	-0.5		0.2		-0.3	
Correct Answers						
mean	23.6±9.8	46.3±19.3	10.3±5.2	41.1±210	33.89757	44.6±17.5
median	25	49	10.0	40.0	34	45
mode	32	62	9.0	36.0	30	39
range	45(0 to 45)	0 to 88.2	25 (0 to 25)	100(0 to 100)	68(0 to 68)	89.5(0 to 89.5)
Skewness	-0.3		0.1		-0.1	
Wrong answers						
mean	10.1 ±5.3	19.8±10.3	4.2±2.9	16.9±11.4	14.3±6.9	18.9±9.1
median	9.0	17.6	4.0	16.0	14	18.4
mode	8.0	15.7	2.0	8.0	10	13.2
range	38 (0 to 38)	74.5 (0 to74.5)	17.0	68.0(0 to 68)	55 (0 to 55)	72.3 (0 to 72.3%)
Skewness	1.3		0.7		1.4	

All except scores, except Overall Scores of OAK, did not approximate normal distribution ($p<0.005$, Kolmogorov-Smirnov Test)
* A correct answer gets 1 point, an "unsure" answer 0 points and a 1 point will be deducted for each wrong answer
# Overall scores, percentage of correct answers and percentage of wrong answers of AP was significantly higher than ATM. $p<0.001$ (Wilcoxon Signed Ranks Test.

4.3.2.1 Influence of socioeconomic and sources of information

For analysis purposes, the educational levels were combined and recoded into three levels; up to primary (from no education up to completion of primary school), secondary (completion of secondary school or ITE), and tertiary (up to A-levels, polytechnic and university). Institute of Technological Education (ITE) institutions serve as post-secondary school technical education for less academically inclined students. It was combined with the secondary school level as the scores of the respondents were closer to secondary school rather than tertiary education level (Figure 4.4). Similarly, the income category was recombined into 4 categories; <SGD1000, SGD1000-2999, SGD3000-4999 and >SGD 5000.

Figure 4.4: Trends of education level vs. mean sum of Overall Asthma Knowledge (OAK)



Factors influencing the overall scores, analyzed using linear regression. Two sets of variables were used in the analysis. The first set of variables consists of the respondent demographics while the second set of variables was the respondent's main sources of information. Independent variables in the first set had seven items: age, gender, race, educational level, family income, healthcare related occupation, and whether knowing someone has asthma. Independent variables in the second set had 11 items. These were ratings of the importance of the following sources of information: family doctors, specialist physicians, pharmacists, nurse, traditional medicine practitioners like sinsehs, internet, radio or television, newspapers, family/friends or relatives, magazines or journals, health brochures/pamphlets and talks/public forums or seminars.

Analysis using respondent characteristics accounted for only 2% to 7.5% of the scores observed. Education affected the number of wrong answers in AP and ATM ($p \leq 0.001$), and also the sum of these two scales. The effect of higher education was positive; associated with in lower number of wrong answers and higher overall scores. Higher family income and age was associated with greater number of correct answers in AP and ATM respectively.

When sources of information were entered into the analysis, these two set of factors accounted for 3% to 10% of the scores observed. Radio and television as important sources of information was positively associated the number of correct answers obtained but not the number of wrong answers obtained. Talks and seminars were associated with decreased number of wrong answers for AP and ATM.

Table 4.5: Multiple linear regression analysis: effect sizes of demographic factors influencing perception (AP), asthma treatment and management (ATM) and overall asthma knowledge (OAK)

Independent Variables	OAK sum	AP sum	AP correct	AP wrong	ATM Sum	ATM correct	ATM wrong
R^2	0.04**	0.04**	0.02	0.07**	0.03**	0.01	0.03**
Constant (SE)	4.61 (2.88)	3.13 (2.12)	17.21 (2.01)	14.1 (1.04)	1.48 (1.05)	7.35 (1.06)	5.86 (0.58)
Education (SE)	2.98 (0.68)**	2.18 (0.52)**		-1.59 (0.26)**	0.82 (0.26)*		-0.69 (0.14)**
Gender(SE)	2.16 (0.86)	1.84 (0.65)*		-0.99 (0.32)**			
Age (SE)					0.35 (0.12)*	0.33(0.12)*	
Family Income (SE)			0.80 (0.39)				
Know someone who has asthma (SE)	1.75 (0.88)				0.67 (0.33)		

Males were coded as 1, and females were coded as 2. Therefore a positive effect size is positively correlated to females
AP-Asthma Perception, ATM-asthma treatment and management, OAK-overall asthma knowledge
SE= Standard Error**$p \leq 0.001$, *$p \leq 0.01$, $p < 0.05$ for all others

Table 4.6: Multiple linear regression analysis: effect sizes of demographic factors and sources of information influencing perception (AP), asthma treatment and management (ATM) and overall asthma knowledge (OAK)

Independent Variables	OAK sum	AP sum	AP correct	AP wrong	ATM sum	ATM correct	ATM wrong
R^2	0.05**	0.04	0.01*	0.08**	0.05**	0.02**	0.04**
Constant	2.423	2.99(1.73)	17.43 (1.82)	17.43 (0.81)	0.001(1.12)#	0.84 (0.71)	0.57 (0.47)
Education	2.72(0.58)**	2.43(0.43)**		-1.55(0.21)**	0.78 (0.23)**		-0.61 (0.12)**
Gender	1.68(0.04)	1.69(0.63)*		-1.02(0.31)**			
Age						0.26(0.11)	
Family Income			0.44(0.19)				
TM	-0.99(0.39)				-0.53 (0.15)**	-0.36(0.15)	
GP	1.25(0.49)				0.66 (0.18)**		
TV	1.50(0.41)	0.76 (0.30)	0.64(0.29)		0.63 (0.15)**	0.65(0.16)**	
Talks/Public seminars				-0.66 (0.14)			-0.30 (0.80)**

Males were coded as 1, and females were coded as 1. Therefore a positive effect size is positively correlated to females
AP-Asthma Perception, ATM-asthma treatment and management, OAK-overall asthma knowledge
SE= Standard Error**$p \leq 0.001$, *$p \leq 0.01$, $p < 0.05$ for all others.

The demographic factors which were shown to significantly affecting the scores were further analyzed using ANOVA or Kruskal-Wallis followed by Mann-Whitney tests as appropriate. ANOVA analysis of OAK sum showed that education was statistically significant ($p<0.005$) and post-hoc analysis showed that the scores of tertiary educated respondents were significantly higher than both primary and secondary level educated respondents ($p<0.05$) secondary level educated respondents ($p<0.05$), (Table 4.7 and Table 4.8) while respondents with family income of less than SGD1000 scored significant lower than respondents from family with income of SGD3000 per month and above ($p<0.05$).

Table 4.7. Post-hoc test of ANOVA analysis of education level vs. sum of OAK score

	Educational Level		
	Primary	**Secondary**	**Tertiary**
Mean Score	15.9±15.4	18.7 ±12.9	22.0±13.6
Primary	-	NS (P=0.064)	P=0.001
Secondary			P=0.001

OAK= Overall asthma Knowledge

The influence of education on other scores was analyzed using Kruskal Wallis, and followed by Mann-Whitney tests (Table 4.8). The difference for each level of education was statistically significant at $p<0.005$ for both AP and ATM section.

Table 4.8: Post-hoc analysis using Mann-Whitney test for education levels

	Educational Level	
	Secondary	**Tertiary**
AP wrong score*		
Primary	P<0.001	P<0.001
Secondary		P<0.001
ATM wrong score*		
Primary	P=0.004	P<0.001
Secondary		P=0.003
Sum AP score*		
Primary	NS (P=0.05)	P<0.001
Secondary		P<0.001
Sum ATM score#		
Primary	P=0.004	P=0.015
Secondary		NS(P=0.04)

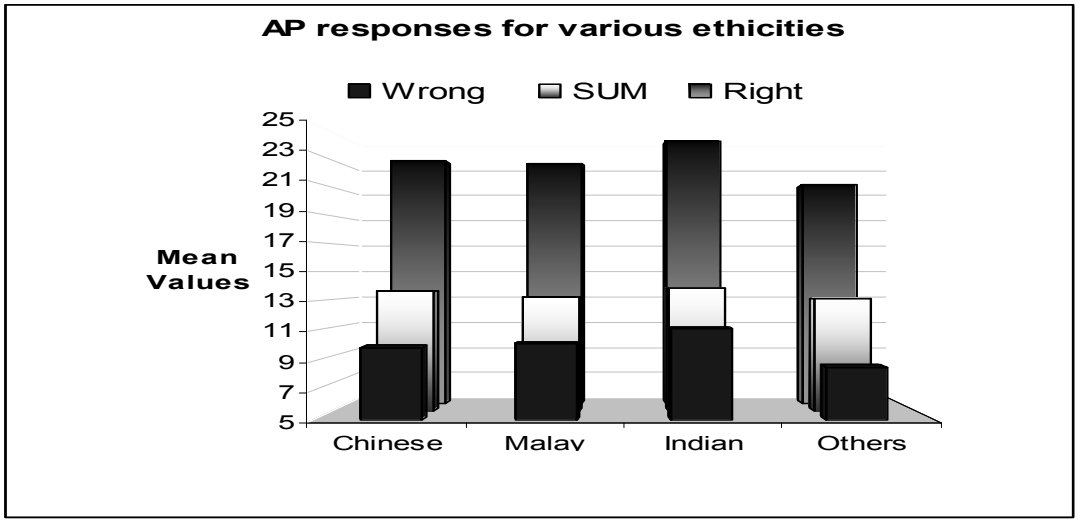
* P<0.001, Kruskal Wallis test
# P<0.05 Kruskal Wallis test

Knowing someone with asthma predicted two scores; the sum of OAK and the sum of ATM in the first model of the regression analysis. Mann Whitney tests showed that respondents who know someone with asthma generally scored higher ($p<0.01$). However the difference was not significant between respondents who had asthma and respondents without asthma ($p=0.06$), respondents' whose family has asthma vs. without ($p=0.46$), and whose relatives have asthma vs. those without ($p=0.78$). However, respondents with a friend or colleague with asthma scored significantly better than those without a friend or colleague with asthma ($p=0.02$).

4.3.2.2 Ethnicity

Ethnicity was also separately analyzed using ANOVA for sum of OAK and Kruskal Wallis and Mann Whitney test for other scores. There was statistical significance in the score number of wrong answers in the AP section. Respondents from the Indian ethnic group had more wrong answers than Chinese ($p<0.001$, Mann Whitney), Malay ($p=0.015$) and other ethnicities ($p=0.002$). However, they also had more number of correct answers for the AP section and the ATM section (not statistically significant), resulting in higher over all score for AP and ATM (not statistically significant). No other significant findings or trends were noticed for ethnicity comparisons.

Figure 4.5: The mean values of responses from various ethnicities in the AP section



4.3.2.3 Asthma patients vs others

Experience with asthma or exposure to other asthma patients were analysed using t-tests (or Mann Whitney for non-normally distributed summary scores). Respondents who knew someone with asthma scored higher that those who did not know any asthmatics or had asthma in both AP and ATM sections ($p<0.02$). There were no significant difference between asthma patients and non-patients, and respondents' with family members or relatives with asthma vs those who did not. However, respondents with a friend or colleague with asthma had better OAK ($p<0.02$), which was contributed with higher overall score in ATM ($p<0.005$) and less misconceptions ($p=0.01$)

Table 4.9: Experience or exposure to asthma patients vs mean percentage scores in OAK, AP and ATM

	OAK sum (%)		Sum of AP (%)		Sum of ATM (%)	
	%	SD	%	SD	%	SD
All respondents, n=1113	25.7	18.1	26.5	20.6	24.2	20.7
Do not know someone with asthma n=428	24.0*	18.3	24.8*	21.2	22.5*	20.7
Know someone with asthma n=685	26.8	17.9	27.5	20.1	25.3	20.7
Respondent has no asthma, n=1009	25.4	18.1	26.1	20.6	24.0	20.7
Respondent has asthma, n=104	28.5	18.1	26.5	19.6	26.3	21.1
No family members with asthma, n=885	25.5	18.2	26.3	20.8	24.0	20.8
Family members with asthma, n=228	26.5	17.6	27.2	19.6	24.9	20.3
No relatives with asthma, n=926	25.7	18.2	26.4	20.7	24.3	20.9
Relatives, n=187	26.0	17.4	27.0	19.7	23.8	19.9
No friends/colleagues/classmates with asthma, n=795	24.9*	18.3	25.8	20.8	23.1**	20.5
Friends/Colleagues/Classmates n=318	27.8	17.4	28.2	20.0	27.2	20.9

*p<0.02, **p<0.005

OAK-Overall asthma Knowledge, AP=Asthma Perception, ATM=Asthma Treatment and management

4.3.3 Item level analysis

Detailed information on the responses to each statement is provided in, Table 4.11 and (D)= "Disagree", (A)="Agree": Answers which were in agreement with these were coded as "correct", and in opposition to these were coded "wrong".

Table 4.12. The following section highlights the most well understood and most common misconception of asthma.

4.3.3.1 Areas of good understanding

The item with the highest number of correct answer was 13d, "Asthmatics can travel without bringing their asthma medications when they are well", with 75.4% of respondents answered correctly (No) to this statement.

Regarding the nature of asthma, 69.6% did not agree that asthma is a temporary problem that will go away without any treatment, 61.8% thought that it can be controlled with proper treatment and 59.9% thought that it can start at any age. In addition, 58.4% of respondents thought that asthma attacks could cause death about the same number also thought that asthma attacks could be prevented (57.1%).

Signs and symptoms of asthma were among the items with highest number of correct answers. The symptoms most recognized by the respondents include: breathlessness (64.6 %), wheezing (56.3%), fast breathing in children (56.9%), and tightness or pain in the chest (54.7%).

Regarding triggers, more than half of respondents (54.8%) correctly agreed that triggers are different for different people. Triggers commonly identified by the respondents included house dust mite (59.9%), haze (59.5%), animals' fur and feathers (58.9%) and tobacco or cigarette smoke (56.3%).

Regarding treatment, the majority of respondents (58.3%) answered correctly that cough mixtures were not for treatment of asthma, while less than 1 in 5 (18.9%) had this wrong idea. More than half of the respondents also correctly agreed that inhalers will only be effective if the patient learn to use it properly (56.7%) and acts faster than those than are taken by mouth (52.3%).

4.3.3.2 Areas of Uncertainty

Generally there are two trends observed for questions with high number of "unsure" responses. The first group consists of questions related to pathophysiology of asthma, pharmacology of medication, and general information about when to use the medications. This group had about equal number of correct and "unsure" answers. The second group consists of questions related to side-effects. This group had low level (around 20% or less) correct answers and about 1/3 incorrect answers.

The top four items with the highest percentage of "unsure" answers were item 19a-19d, which were about inhaled steroids (47.4% to 53.1%). Other than question 19d, ("Are not the same steroids as used by sportsmen/athletes"), the rest of these items had 31.7% to 41.2% wrong answers). Question 15b ("Inhalers cause more side-effects than those that are taken by mouth) also displayed a similar pattern, with 42% unsure answers and 28.5% wrong answers.

4.3.3.3 Common misconceptions

The most common misconceptions were related to causes or triggers of asthma, the role of food and also the risk versus benefits of long term treatments. The item with the highest number of wrong answers was item (1e): "What causes asthma? Dusty

environment?" More than half of respondents (58.5%) agreed to the statement. While dusty environment were thought to cause asthma, 49.2% did not think that family members who coughed a lot when they were young could be a part of the positive history of asthma in the family and therefore increases the risk of asthma.

Cold food or drinks were attributed as the cause and triggers of asthma; with 52.9% of respondents thought that cold drinks or cold air triggers asthma and 47.3% believed that taking too much cold drinks or food could cause asthma.

Misconceptions about long term medication use were also high, with 37.7% responding believing that "All asthmatics only need to take medications when they are not well". In addition%, 41.2% believed that inhaled steroids should not be used long term as it will dependence; 32% also believed that inhaled steroids can cause stunted growth in children (48.9% were unsure), 31.7% believed that it can cause problems like poor memory in children (47.4% were unsure).

The other top misconceptions were also related, with 36.1% of respondents believed that "asthma is a common childhood problem that will go away when the child is older and stronger", and that it "can be totally cured" (38.4% agreed, 30.5% unsure, 33.8% disagreed). A sizeable proportion (32.7%) of respondents believed that Traditional Chinese Medicine can cure asthma, with only 27.5% disagreeing. Approximately, the same number of respondents (32.8%) thought that acupuncture could cure it. As many as 25.6% thought eating crocodile meat could cure asthma, while another 36.1% were unsure. Even more surprisingly, eating a live mice to cure asthma was believed to be effective by as much as 18% (almost 1 in 5!), with another 30.8% was

unsure. The number of people who believed in the effectiveness of these unproven, if not weird alternative cure was more than those who trusted using inhaled steroids long term without dependence (10.9%), and almost the same as the number of people who thought that using inhaled steroids will not cause stunted growth (19.1%) and memory problems (20.9%).

The other misconceptions were related to triggers. Only 30.8% knew that triggers were more commonly found at home than in the outside environment with 41.3% mistakenly thought that cleaning the house with a broom or duster is effective in removing indoor triggers. 40.2% did not recognise that exercise is a trigger for asthma attacks (Exercise Induced asthma).

Most signs and symptoms of asthma were well recognised, except young children's refusal to eat, where only 28.5% agreed, and 28% disagreed.

Table 4.10: Percentages of Correct, Wrong and Unsure answers in the Asthma Perception Section

Questions (Answer)	%Correct	%Unsure	%Wrong
1. What causes asthma?			
1a Emotional problems (D)	47.2	27.6	25.1
1b Airways sensitive (A)	54.1	34.8	11.1
1c Poor nutrition* (D)	42.7	28.5	28.8
1d Air-conditioner (D)	36.0	30.4	33.6
1e Dusty environment (D)	9.2	32.3	58.5
Average	37.8	30.7	31.4
2. Asthma			
2a can be totally cured (D)	31.1	30.5	38.4
2b can start at any age (A)	59.9	34.0	6.1
2c common childhood problem, will go away later (D)	30.9	33.0	36.1
2d temporary problem, will go away without treatment (D)	69.6	15.4	15.0
2e controllable by treatment(A)	61.8	34.3	4.0
Average	43.7	30.1	26.2
3. Risk of asthma			
3a family members has asthma (A)	48.9	31.7	19.3
3b History of childhood cough among family members(A)	23.1	27.6	49.2
3c has other sensitivity or allergy(A)	40.8	39.0	20.2
Average	37.6	32.8	29.6
4. Can these increase the risk of getting asthma?			
4a Take too much cooling food/cold drinks(D)	20.8	31.9	47.3
4b Bath early in the morning /late at night often(D)	49.9	25.8	24.3
4c Constant exposure to chemicals e.g. paint, latex(A)	46.0	37.1	16.9
Average	38.9	31.6	29.5
5. A mother who smokes during her pregnancy will make her baby more likely to get asthma(A)	44.9	40.8	14.3
6. Symptoms of asthma include			
6a breathlessness or trouble breathing in and out(A)	64.6	32.9	2.5
6b tightness / Pain in the chest(A)	54.7	34.3	10.9
6c wheezy or noisy breathing(A)	56.3	35.1	8.6
6d lots of coughing, especially at night(A)	48.2	37.8	14.0
Average	56.0	35.0	9.0
7. In children, the warning signs of a coming asthma attack include:			
7a Prolonged coughing(A)	52.7	37.4	10.0
7b Fast breathing(A)	56.9	36.6	6.5
7c Refusing to eat(A)	28.5	33.5	38.0
7d Restless or tired(A)	44.0	38.4	17.6
Average	51.3	35.7	13.0

(D)= "Disagree", (A)="Agree": Answers which were in agreement with these were coded as "correct", and in opposition to these were coded "wrong".

Table 4.10: Percentages of Correct, Wrong and Unsure answers in the Asthma Perception Section (Con't)

Questions	%Correct	%Unsure	%Wrong
8. During asthma attack, the airways become			
8a swollen (inflammation) (A)	42.3	44.4	13.2
8b narrow(A)	51.5	42.6	5.9
8c blocked by thick mucus(A)	46.3	42.2	11.5
Average	46.7	43.1	10.2
9. Asthma attacks can			
9a cause death(A)	58.4	35.9	5.8
9b cause long term damage to lungs(A)	49.2	41.5	9.3
9c be prevented(A)	57.1	36.2	6.8
Average	54.9	37.9	7.3
10. Which of these can start off an asthma attack?			
10a Flu or viral infections(A)	52.1	35.4	12.5
10b Exercise(A)	33.8	26.0	40.2
10c House dust mite(A)	59.9	32.9	7.2
10d Food preservatives, additives or colouring(A)	35.9	35.9	28.3
10e Tobacco smoke (cigarette smoke) (A)	56.3	35.7	8.0
10f Mental or emotional stress(A)	42.0	36.8	21.2
10g Animals: fur and feathers(A)	58.9	34.7	6.4
10h Food: bird's nest, peanuts, seafood, milk, oranges(A)	35.6	33.4	31.0
10i Cold drinks/cold air(D)	12.8	34.3	52.9
10j Haze (A)	59.5	35.3	5.2
Average	44.7	34.0	21.3
11. Trigger factors are			
11a different for different people (A)	54.8	38.0	7.2
11b found more commonly at home than the outside environment(A)	30.8	35.9	33.3
Average	42.8	36.9	20.2
12. Which steps are effective in reducing trigger factors in the environment?			
12a. Wash bed sheets in hot water at least once a week(A)	52.7	37.1	10.2
12b. Clean the house with a broom or duster(D)	29.9	28.8	41.3
12c. Clean or change the air-conditioner filter frequently(A)	56.4	37.6	6.0
Average	46.3	34.5	19.2
13. Which of these statements are CORRECT? Asthmatic CAN			
13a. do exercises(A)	54.6	33.0	12.4
13b. go near people who are smoking (D)	52.1	21.5	26.4
13c. travel to cold countries(A)	43.7	32.6	23.7
13d. travel without bringing their asthma medications when they are well(A)	75.4	11.7	12.9
13e. take medicines before exercise to prevent an attack brought on by exercise(A)	42.6	38.0	19.4
Average	53.7	27.4	19.0

(D)= "Disagree", (A)="Agree": Answers which were in agreement with these were coded as "correct", and in opposition to these were coded "wrong".

Table 4.11: Percentages of Correct, Wrong and Unsure answers in the Asthma Treatment and Management (ATM) Section

14. Which of these statements are CORRECT?	**%Correct**	**%Unsure**	**%Wrong**
14a All asthmatics only need to take medications when they are not well(D)	38.7	23.6	37.7
14b Cough mixtures are used to treat asthma(D)	58.3	22.8	18.9
14c Traditional Chinese Medicine can cure asthma(D)	27.5	39.8	32.7
14d Asthma can return at a later age even when a child seems to get better when growing up(A)	53.7	37.4	8.8
Average	44.6	30.9	24.5
15. Asthma medications which are inhaled			
15a. better than oral (A)	45.5	42.3	12.2
15b cause more side-effects than oral(D)	29.5	42.1	28.5
15c can cause addiction(D)	39.0	33.5	27.4
15d goes directly to the lungs(A)	51.2	40.7	8.1
15e acts faster than oral(A)	52.3	41.4	6.3
15f only effective if patient learn to use it properly(A)	56.7	39.4	3.9
Average	45.7	39.9	14.4
16. Two main types of medications: preventers(controllers) and relievers (A)	50.2	44.8	5.0
17. Quick relievers-salbutamol (Ventolin)			
17a. quickly stop an asthma attack (A)	50.8	40.4	8.8
17b. should only use when there are symptoms(A)	50.0	42.5	7.6
17c. acts by opening up the airways(A)	49.4	46.5	4.1
17d. should not use in the long-term to prevent asthma(A)	42.3	45.8	12.0
Average	48.1	43.8	8.1
18. Preventative medications			
18a. make airways less sensitive to triggers and irritants(A)	49.0	45.9	5.0
18b. only needed when asthma symptoms are frequent(A)	42.5	42.4	15.1
18c. do not stop asthma symptoms quickly(A)	38.8	45.0	16.1
18d. may take a few weeks before effects noticed	33.9	46.8	19.3
18e. used everyday even when an asthmatic is well(A)	34.3	41.1	24.6
18f. improve asthma and reduce visits to doctors(A)	48.9	43.6	7.5
Average	41.2	44.2	14.6
19. Inhaled steroids			
19a. can cause stunted growth in children(D)	19.1	48.9	32.0
19b. can cause poor memory in children(D)	20.9	47.4	31.7
19c. should not use a long time; patient will depend on it(D)	10.9	47.9	41.2
19d. not the same as used by sportsmen/athletes(A)	37.6	53.1	9.4
Average	22.1	44.2	14.6

(D)= "Disagree", (A)="Agree": Answers which were in agreement with these were coded as "correct", and in opposition to these were coded "wrong".

Table 4.12 Percentages of Correct, Wrong and Unsure answers for other items related to perception about asthma

20. Asthma and pregnancy	**%Correct**	**%Unsure**	**%Wrong**
20a Is it safe for an asthmatic woman to get pregnant? (Y)	43.0	40.3	16.7
20b Asthmatic women should continue taking their anti-asthma medicine (Y)	41.6	46.6	11.8
Average	42.3	43.5	14.2
21. Do you think these treatments could be effective in treating asthma?			
21a Eating crocodile meat (N)	38.3	36.1	25.6
21b Eating live mice (N)	51.2	30.8	18.0
21c Acupuncture (N)	25.3	41.9	32.8
Average	38.3	36.3	25.5

(Y)= "Yes, (N)="No", Answers which were in agreement with these were coded as "correct".

4.3.3.4 Variables predictive of responses

Multinomial logistics regression was used to analyse influence of factors at the item level, and a forward entry stepped model were used. The predictor variables used in this analysis was as shown in Table 4.13

Table 4.13: Predictor variables and coding used in Item level multinomial regression analysis

Predictor variables	
Respondent characteristics	
Gender	1=male, 2=female
Age	1=16-20, 2=21-30, 3=31-40, 4=41-50,5=51-60, 6=>60
Ethnicity	1=Others, 2=Indians, 3= Malays, 4= Chinese
Education	1= Primary, 2= Secondary, 3= Tertiary
Family Income (per month)	1≤1000, 2=1000-2999, 3=3000-4999, 4≥5000
Health care related occupation	No=0, Yes=1
Know someone with asthma	No=0, Yes=1
Source of information: 1= ("quite important", "important" and "very important"), ("not important at all", "not important")	

The importance of sources information was categorised and recoded into 2 categories: "important" ("quite important", "important" and "very important"), and "not important" ("not important at all", "not important"). The method used in determining the categories in the new codes were similar as used in recoding education and income, ie using charts to see the trend of answers. Coding the 5 categories in to a binary level category improved the models.

Of the 76 items in OAK, the model had significant model fit ($p<0.05$), except for item 18b ("preventer are only needed when there are symptoms) and 7c (Refusing to eat). The range of variance predicted, as indicated by pseudo R^2 from 0.8 to 10.2%. All predictor variables in this model predicted at least 1 item. The results are shown in

4.3.3.5 Role of ethnicity in the item level

Several items were predicted by ethnicity using multinomial regression.

Compares to Chinese respondents, the odds ratio of Malay respondents in wrongly thinking that "poor nutrition" causes asthma (item 1c) was 2.32 (95% CI: 1.60 to 3.36, $p<0.005$). Malay respondents were also more likely to answer "unsure" to this question (Odds ration: 2.01, 95% CI 1.39 to 2.90, $p<0.005$) compare to Chinese respondents. However, Malays were more likely to fail to identify certain food like oranges and bird nest could be an asthma trigger (Odds ratio: 1.81, 95% CI: 1.10 to 2.98, $p<0.05$).

Ethnicity was a predictor for items in Question 4 (Can these actions increase the risk of getting asthma?) More Indians (57.8%) and Malays (51.6%) answered "Yes" compared to Chinese (42.5%) on choice of "Take too much cooling food/cold drinks". (Odds ratio for Malays: 1.67, 95% CI 1.08 to 2.59, $p<0.05$, Odds ratio for Indians was 1.83 95%CI 1.17to2.85, $p<0.01$). More Indians (37.2%) and Malays (32.6%) also believed that taking a bath early in the morning or late night often could increase the risk of getting asthma (Question 4b) [Odds ratio for Indians: 3.26, 95% CI: 2.20 to 4.85 $p<0.005$, Odds ratio for Malays: 2.89, 95% CI: 1.99 to4.21, $p<0.005$]

Malays and Indians did better in two items related to symptom identification. The percentage of respondents who answered Question 7d ["In children, the warning signs of a coming asthma attack include: restless or tired"] correctly were lower in Chinese. In comparison, 47.5% of Indians and 48.7% of Malays answered correctly in contrast to 10.8% of Chinese (Odds ratio for Indians: 0.57, 95% CI: 0.35 to 0.92, $p<0.05$, Malays: 0.50, 95% CI: 0.32 to 0.77, $p<0.005$). The Chinese were also more likely to get it wrong compared to Malays in whether smoking during pregnancy increases risk of asthma (Question 5, Odds ratio: 1.85, 95% CI: 1.14 to 3.03).

Indians are more likely to think that asthma attacks *do not* cause death (odds ratio: 2.79, 95% CI: 1.50 to 5.19, $p<0.005$). A bigger proportion of Indians (47.7%-wrong, 29.1%-correct) Indians also failed to identify that exercise as a trigger (Question 10b) Odds ratio: 1.65, 95% CI: (1.11, 2.46) $p<0.005$). More Indians (51%) than Malays (38.3%) or Chinese (38.8%) believed that "Clean the house with a broom or duster"

(Question 12b) would be effective in "reducing trigger factors in the environment", (Odds ratio: 2.08, 95% CI: 1.38 to 3.12, $p<0.005$).

In terms of asthma treatment, more Malays (Odds ratio: 1.76 95%CI: 1.24 to 2.49 $p<0.005$) were like to mistakenly thought that asthma medicines *only* need to be taken when unwell [Question 14a]. However, more Chinese respondents (37%) thought that "Traditional Chinese Medicine (TCM) can cure asthma" (Question 14c), compared to 22.2% Indian respondents (Odd ratio: 2.38, 95% CI: 1.54 to3.70, $p<0.005$), and 29.1% Malays (not significant). About 4 in 10 in each ethnicity (39.4% to 40.3%) chose the unsure option to this question.

Table 4.14 (1)a: Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP) –respondent characteristics

1. What causes asthma?	*R^2	Respondent characteristics				
		Gender	Ethnicity	Education	Health care	Know SO
1a Emotional problems***	2.0a					
1b Airways sensitive wrong	3.4c	1.52a (1.01,2.29)		Pri: 2.58c (1.45, 4.59) Sec 2.08c (1.27, 3.38)		1.71a (1.13,2.57)
1c Poor nutrition wrong unsure	4.2c	 1.52b (1.13,2.04)	Mal: 2.32c (1.60, 3.36) Mal: 2.01c (1.39,2.90)			
1d Air-conditioner wrong	3.3c			Pri: 1.97c (1.28, 3,04)		
1e Dusty environment wrong unsure	4.9c				2.45a (1.01, 5.95)	- 0.45c (0.32,0.77) 0.59a (0.37,0.94)

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. .
[a]P<0.05, [b]P<0.01, [c]P<0.005

Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Pri= Primary, Sec= Secondary Level

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma.

* ** No respondent characteristic was a significant factor for question 1a.

Table 4.14 (1)b: Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

1. What causes asthma?	Source of Information						
	Specialist	TMP	Fam & Fr	Newspapers	Magazines	Brochures	Talks
1a Emotional problems wrong					0.56 a (0.37, 0.87)		0.60a (0.40, 0.91)
1b Airways sensitive**							
1c Poor nutrition wrong		0.63 (0.46,0.86)					
1d Air-conditioner wrong			0.61a (0.42, 0.90)				
unsure	1.80a (1.06, 3.08)					0.54a (0.33, 0.89)	
1e Dusty environment wrong				0.47c (0.28, 0.79)			
unsure				0.54a (0.31,0.93)			

TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

** No source of information was a significant factor for question 1b.

[a]P<0.05, [b]P<0.01, [c]P<0.005

Table 4.14(2a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics

2. Asthma	*R^2	Respondent characteristics				
		Age	Ethnicity	Education	Healthcare	Income
2a can be totally cured wrong unsure	3.3c					3K-3999: 1.98a (1.08, 3.61) <1000 : 2.93b (1.37,6,26) 1K-2999: 2.83b (1.37,5.84) 3K-4999: 3.59c (1.17,7.62)
2b can start at any age wrong unsure	4.5c		Ind 0.57c (0.39,0.83)	Pri 3.70c (1.84, 7.42)	0.49a (0.28, 0.87)	
2c common childhood problem, will go away later wrong unsure	8.1c	0.40a (0.19,0.82)		Pri 2.15c (1.30,3.57) Sec 1.53a (1.08,2.17)		

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*R2 = Pseudo R 2, , Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Pri= Primary, Sec= Secondary Level
"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma.
[a]P<0.05, [b]P<0.01, [c]P<0.005

(Continued) **Table 4.14 (2)a: Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics**

2. Asthma	*R^2	Respondent characteristics		
		Gender	Ethnicity	Education
2d temporary problem, will go away without treatment	5.0c			
wrong				Pri 2.02a (1.67,3.49)
				Sec 1.56a (1.02,2.37)
unsure		1.81c (1.28,2.56)		Pri 1.91a (1.12,3.28)
				Sec 1.56a (1.04,2.32)
2e controllable by treatment	5.3c			
wrong		2.16a (1.11,4.23)		Pri 3.93c (1.61,9.62)
unsure			Oth 2.06a (1.05,4.04)	
			Ind 0.64a (0.44,0.93)	

*R2 = Pseudo R 2, , Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma.

[a]P<0.05, [b]P<0.01, [c]P<0.005

Table 4.14 (2)b: Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

2. Asthma	Information source				
	TMP	Fam & Fr	TV	Magazines	Talks
2a can be totally cured					
wrong	0.72a (0.53,0.98)			2.02c (1.36, 3.00)	
unsure	0.69a (0.50,0.96)			1.93a (1.14,2.63)	
2b can start at any age**					
2c common childhood problem, will go away later					
wrong		0.56c (0.38, 0.83)	1.76a (1.12,2.74)		
unsure		0.51c (0.34,0.77)	1.74a (1.11,2.75)		
2d temporary problem, will go away without treatment**					
2e controllable by treatment					
wrong					2.07a (1.04,4.13)

TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

** No source of information was a significant factor for question 2b and 2d.

[a]P<0.05, [b]P<0.01, [c]P<0.005

Table 4.14 (3a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics

3. Risk of asthma	*R^2	Respondent characteristics					
		Gender	Ethnicity	Education	Health care	Income	Know SO
3a family members has asthma	6.7c						
Wrong		1.88 c (1.35,2.63)		Pri 2.33 c (1.46,3.73) Sec 1.80 c (1.22,2.67)			
Unsure			Ind 0.59 b (0.39,0.87)	Pri 0.65 a (0.42,1.00)			
3b History of childhood cough among family members	8.4c						
Wrong				Pri 0.48 c (0.3,0.76) Sec 0.64 a (0.45,0.93)		<1000: 0.37 a (0.17,0.84) 3K-4999: 0.36 a (0.17,0.79)	0.63 c (0.46,0.86)
Unsure				Pri 0.57 a (0.34,0.97)	3.33 a (1.15,9.66)		0.57 c (0.4,0.81)
3c has other sensitivity or allergy	4.4c						
Wrong				Pri 2.15 c (1.32,3.49) Sec 1.64 a (1.1,2.42)			

*R2 = Pseudo R 2, , Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma.

[a]P<0.05, [b]P<0.01, [c]P<0.005

Table 4.14 (3b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

3. Risk of asthma	Information source		
	Nurses	TMP	Newspapers
3a family members has asthma Wrong	1.70 a (1.13,2.54)		
3b History of childhood cough among family members Wrong		1.55 b (1.13,2.14)	
3c has other sensitivity or allergy Wrong			2.06 c (1.26,3.37)

TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

Table 4.14 (4a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics

4. Can these increase the risk of getting asthma?	*R^2	Respondent characteristics				
		Ethicity	Education	Health care	Income	Know SO
4a Take too much cooling food/cold drinks	9.9c					
Wrong		Ind: 1.67 a (1.08,2.59) Mal: 1.83 b (1.17,2.85)	Pri: 2.09 b (1.25,3.5) Sec: 2.08 c (1.42,3.06)	3.28 c (1.58,6.81)	<1000 2.3 a (1.12,4.7)	0.63 b (0.45,0.89)
Unsure		Oth: 3.81 a (1.25,11.59)	Sec: 1.9 c (1.26,2.86)		<1000: 4.33 c (1.92,9.76) 3K-4999: 2.42 a (1.17,5.04)	
4b Bath early in the morning /late at night often	9.2c					
Wrong		Ind: 3.26 c (2.2,4.85) Mal 2.89 c (1.99,4.21)				
Unsure		Oth: 5.08 c (2.38,10.88) Mal: 1.72 c (1.19,2.49)				
4c Constant exposure to chemicals e.g. paint, latex***	1.0a					
5. Smoking during pregnancy makes baby' s asthma risk	3.9c					
Wrong		Mal: 0.54 a (0.33,0.88)				
Unsure			Pri: 0.64 a (0.43,0.95)			

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. . [a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others,

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma. .

* ** No respondent characteristic was a significant factor for question 4c.

Table 4.14 (4b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

4. Can these increase the risk of getting asthma?	Information source	
	Nurses	Talks
4a Take too much cooling food/cold drinks**		
4b Bath early in the morning /late at night often**		
4c Constant exposure to chemicals e.g. paint, latex		
Unsure		0.7 a (0.49,0.99)
5. Smoking during pregnancy makes baby' s asthma risk		
Wrong	1.85 b (1.2,2.85)	

TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

** No Source of Information was a significant factor for question 4a and 4b.

Table 4.14 (5a & b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)

6. Symptoms of asthma include	*R^2	Respondent characteristics						Information source	
		Ethnicity		Education		Health care	Know SO	Fam & Fr	TV
6a breathlessness	5.3c								
Wrong		Oth	5.81 a (1.11,30.5)	Pri	8.86 c (2.31,33.92)				
				Sec	3.73 a (1.02,13.63)				
Unsure		Ind	0.5 c (0.34,0.74)			0.4 c (0.23,0.69)			
6b tightness / Pain in the chest	3.1c								
Wrong				Pri	2.49 c (1.44,4.3)			1.99 c (1.26,3.13)	
				Sec	1.7 a (1.05,2.74)				
6c wheezy or noisy breathing	5.8c								
Wrong							1.89 b (1.19,2.97)		2.08 b (1.21,3.58)
Unsure		Ind	0.43 c (0.29,0.64)			0.39 c (0.22,0.7)	1.41 a (1.07,1.86)		1.64 b (1.15,2.34)
6d lots of coughing, especially at night***	3.8c								

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends, TV= Radio and Television.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

*** No respondent characteristic or information source was a significant factor for question 6d.

Table 4.14 (6a & 6b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)

7. In children, the warning signs of a coming asthma attack include:	*R^2	Respondent characteristics				Information source
		Ethnicity	Health care	Income	Know SO	TV
7a Prolonged coughing	4.8c					
Wrong				<1000: 0.29c (0.13,0.63) 3K-4999: 0.26 c (0.13,0.54) >5000 0.21c (0.10,0.46)	2.016 c (1.315,3.093)	
Unsure					1.48 b (1.129,1.94)	
7b Fast breathing	3.7c					
Wrong			0.31 a (0.12,0.8)		2.02 b (1.2,3.38)	2.07 a (1.07,3.99)
Unsure			0.47 a (0.26,0.84)			1.66 a (1.13,2.46)
7c Refusing to eat***	0c					
7d Restless or tired	2.6c					
Wrong		Ind: 0.57 a (0.35,0.92) Mal: 0.5 c (0.32,0.77)				

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends, TV= Radio and Television.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

*** No respondent characteristic or information source was a significant factor for question 7c.

Table 4.14 (7a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics

8. During asthma attack, the airways become	*R^2	Respondent characteristics					
		Gender	Ethnicity		Education		Know SO
8a the airways become swollen (inflammation)	2.6c						
8b the airways become narrow	1.9c						
Wrong		2.3 c (1.32,3.99)					
8c the airways is blocked by thick mucus	4.2c						
Wrong					Sec	0.57 a (0.35,0.92)	
Unsure					Pri	0.66 a (0.44,1)	
9. Asthma attacks can							
9a can cause death	2.6c						
Wrong			Ind	2.79 c (1.5,5.19)			2.08 b (1.21,3.56)
9b can cause long term damage to lungs	6.8c						
Wrong		1.69 a (1.08,2.65)					
Unsure			Ind	0.64 a (0.45,0.92)	Sec	1.35 a (1.01,1.81)	
			Mal	0.7 a (0.51,0.97)			
9c can be prevented	2.7c						

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. .
[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others,

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma. .

* ** No respondent characteristic was a significant factor for question 8a and 9c.

Table 4.14: Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

8. During asthma attack, the airways become	Information source							
	Specialist	GP	Pharmacist	TMP	Internet	TV	Magazines	Talks
8a the airways become swollen (inflammation)								
Wrong					2.32 c (1.56,3.47)			
Unsure				0.69 b (0.52,0.9)				
8b the airways become narrow								
Wrong			2.32 b (1.28,4.19)					
8c the airways is blocked by thick mucus								
Wrong	0.35 a (0.13,0.91)	5.93 c (2.29,15.37)						
9. Asthma attacks can								
9a can cause death**								
9b can cause long term damage to lungs								
Wrong						3.06 c (1.63,5.76)	0.29 c (0.13,0.62)	
9c can be prevented								
Wrong			2.23 b (1.26,3.92)					2.22 c (1.28,3.85)

GP= General Practitioner TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005, ** No Source of Information was a significant factor for question 9a.

Table 4.14 (8a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics

10. Which of these can start off an asthma attack?	*R^2	Respondent Characteristics			
		Gender	Ethnicity	Education	Know SO
10a Flu or viral infections Wrong	4.3c			Pri: 2.14 b (1.22,3.76) Sec: 1.84 a (1.15,2.94)	
10b Exercise Wrong Unsure	9.3c		Ind: 1.65a (1.11,2.46)	Sec: 1.88 c (1.33,2.66) Sec: 1.56 a (1.06,2.28)	0.67a (0.50,0.91) 0.67a (0.48,0.94)
10c House dust mite***	2.5c				
10d Food preservatives, additives or colouring***	2.1c				
10e Tobacco smoke (cigarette smoke) Wrong	6.3c			Pri: 3.71 c (1.98,6.95)	
10f Mental or emotional stress Wrong	3.2c				1.46a (1.05,2.03)
10g Animals: fur and feathers Wrong Unsure	5.6c	1.94a (1.16,3.24)	Ind: 0.49c (0.34,0.72)		
10h Food: e.g. bird's nest, peanuts, seafood, cow's milk, oranges Wrong	3.4c		Mal: 1.81a (1.1,2.98)		
10i Cold drinks/cold air***	2.7c				
10j Haze	3.4c				
Wrong Unsure		2.22b (1.25,3.95)	Ind: 0.61b (0.43,0.88) Mal: 0.72a (0.52,0.99)		

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. [a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others,

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma.

*** No respondent characteristic was a significant factor for question 10c, 10d, and 10i.

Table 4.14 (8b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

10. Which of these can start off an asthma attack?	Information source						
	Specialist	GP	Pharmacist	Fam & Fr	TV	Brochures	Talks
10a Flu or viral infections Wrong	0.35 a (0.14,0.85)		1.64 a (1,2.67)			2.03 a (1.18,3.5)	
10b Exercise Wrong						0.48 c (0.3,0.77)	
10c House dust mite Wrong Unsure		2.69 a (1.12,6.49) 1.92 a (1,3.66)					2.22 c (1.32,3.74)
10d Food preservatives, additives or colouring Wrong							1.69 c (1.18,2.42)
10e Tobacco (cigarette) smoke Wrong Unsure				2.19 c (1.31,3.66)	1.71 b (1.18,2.49)		2.03 b (1.21,3.39) 0.66 a (0.46,0.95)

Table continued next page

GP= General Practitioner TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends, TV= Radio and Television.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

(Continued) **Table 4.14 (8b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources**

10. Which of these can start off an asthma attack?	Information source					
	Specialist	**Nurses**	**Fam & Fr**	**TV**	**Brochures**	**Talks**
10f Mental or emotional stress Wrong						2.12 c (1.46,3.1)
10g Animals: fur and feathers Wrong Unsure		1.46 a (1.03,2.05)		1.78 c (1.24,2.56)		2.06 a (1.16,3.68)
10h Food: e.g. bird's nest, peanuts, seafood, cow's milk, oranges						
10i Cold drinks/cold air Wrong Unsure	2.03 a (1.17,3.53)					1.71 c (1.19,2.47)
10j Haze Wrong					2.58 b (1.33,4.98)	

GP= General Practitioner TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends, TV= Radio and Television.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

** No Source of Information was a significant factor for question 10h.

Table 4.14 (9a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–respondent characteristics

11. Trigger factors are	*R^2	Respondent Characteristics			
		Gender	Age	Ethnicity	Education
11a are different for different people Wrong Unsure	5.2c				 Pri: 2.26a (1.12,4.59) Sec: 2.09a (1.16,3.77) Sec: 1.42a (1.07,1.89)
11b are found more commonly at home than the outside environment***	1.4a				
12. Which steps are effective in reducing trigger factors in the environment?					
12a Wash bed sheets in hot water at least once a week Unsure	4.3c		 1: 2.86 c (1.42,5.75) 2: 2.65 c (1.37,5.12) 3: 2.44 b (1.25,4.75) 4: 2.65 b (1.33,5.29) 5: 2.07 a (1.01,4.27)		
12b Clean the house with a broom or duster Wrong Unsure	6.7c		1: 3.12 c (1.51,6.45) 1: 3.7 c (1.63,8.39)	Oth: 3.63 a (1.32,9.97) Ind: 2.08 c (1.38,3.12) Oth: 3.36 a (1.17,9.62)	
12c Clean or change the air-conditioner filter frequently Wrong	8.7c	1.93a (1.11,3.34)			 Pri 4.43c (1.89,10.4) Sec 3.41c (1.58,7.37)

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. . [a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others.

For Age, 1=16-20, 2=21-30, 3=31-40, 4=41-50 years old

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma. .

* ** No respondent characteristic was a significant factor for question 11b.

Table 4.14 (9b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)–information sources

11. Trigger factors are	**Information source**					
	GP	**TMP**	**Fam & Fr**	**TV**	**Newspapers**	**Talks**
11a are different for different people						
Wrong			2.31 c (1.34,3.98)			
Unsure	2.03 a (1.08,3.8)				1.89 c (1.28,2.78)	
11b are found more commonly at home than the outside environment **						
12. Which steps are effective in reducing trigger factors in the environment?						
12a Wash bed sheets in hot water at least once a week						
Unsure					1.9 c (1.28,2.83)	0.69 a (0.48,0.99)
12b Clean the house with a broom or duster**						
12c Clean or change the air-conditioner filter frequently						
Wrong						2.72 c (1.49,4.94)
Unsure	2.56 b (1.32,4.96)	0.67 c (0.51,0.88)		2.28 c (1.58,3.29)		

GP= General Practitioner TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends, TV= Radio and Television

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

** No Source of Information was a significant factor for question 11b and 12 b.

Table 4.14 (10a & b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Perception (AP)

13. Which of these statements are CORRECT? Asthmatic CAN	*R^2	Demographics			Information source
		Gender	Age	Education	Talks
13a Asthmatics can do exercises Wrong Unsure	8.9c			Pri: 10.95c (5.94,20.22) Sec: 4.72c (2.65,8.41) Sec: 1.48 b (1.11,1.97)	
13b Asthmatics can go near people who are smoking Wrong Unsure	8.2c		16-20: 2.42a (1.12,5.21)	Pri: 0.52 b (0.33,0.84) Sec: 0.45 c (0.32,0.63)	
13c Asthmatics can travel to cold countries Wrong	10.2c		21-30: 0.42a (0.2,0.9)	Pri: 4.46 c (2.68,7.43) Sec: 2.72 c (1.82,4.06)	
13d Asthmatics can travel without bringing their asthma medications when they are well Wrong Unsure	2.4c	1.94c (1.32,2.85)			1.84 c (1.22,2.78)
13e Asthmatics can take medicines before exercise to prevent an attack brought on by exercise***	2.5a				

*R^2 = Pseudo R^2, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

*** No respondent characteristic or information source was a significant factor for question 13e.

Table 4.15 (1a & b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)

14. Which is CORRECT?	*R^2	Demographics				Information source			
		Ethicity	Education	Health care	Specialist	TMP	Fam & Fr	Newspapers	Talks
14a All asthmatics only need to take medications when unwell	6.8c								
Wrong		Mal: 1.76 c (1.24,2.49)							1.9 c (1.32,2.75)
Unsure		Ind: 0.61 a (0.39,0.97)							1.87c (1.24,2.82)
14b Cough mixtures treat asthma	5.5c								
Wrong			Pri: 1.9 a (1.17,3.09)						
Unsure			Sec: 1.54a (1.09,2.17)		1.4 a (1.02,1.93)				
14c TCM can cure asthma	7.5c								
Wrong		Ind: 0.42 c (0.27,0.65)			1.54 a (1.1,2.15)	1.92 c (1.24,2.99)	0.43 c (0.3,0.61)		
Unsure		Ind: 0.63 a (0.43,0.94)		2.47b (1.26,4.84)			0.71 a (0.51,0.98)		
14d Asthma can return later even when a child seems to get better	4.2c								
Wrong			Pri: 3.86c (2.07,7.19) Sec: 1.96 a (1.12,3.43)						
Unsure								1.74c (1.21,2.49)	

*R^2 = Pseudo R^2, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

Table 4.15 (2a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)

15. Asthma medications which are inhaled	*R^2	Respondent Characteristics			
		Education	Health care	Income	Know SO
15a better than oral Unsure	3.3c	Pri: 0.50 c (0.34,0.74) Sec: 0.59 c (0.44,0.78)			
15b cause more side-effects than oral Wrong Unsure	3.0c		 3.86c(1.93,7.72)		1.40a (1.01,1.95)
15c can cause addiction***	0.8a				
15d goes directly to the lungs***	3.2c				
15e acts faster than those than oral Wrong	3.0c	Pri: 2.69 c (1.36,5.33)			
15f only effective if patient use properly Wrong Unsure	8.3c	Pri: 5.52 c (1.99,15.32) Sec: 3.03 a (1.19,7.75) Pri: 0.58 a (0.38,0.89)		2K-2999: 0.15 c (0.05,0.45) 3k-4999: 0.18 c (0.06,0.58)	

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. .
[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma. .

* ** No respondent characteristic was a significant factor for question 15c and 15d.

Table 4.15 (2b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)–information sources

15. Asthma medications which are inhaled	Information source					
	Specialist	GP	TMP	TV	Newspapers	Magazines
15a better than oral Wrong Unsure	 2.24 a (1.17,4.31) 1.99 b (1.21,3.25)					
15b cause more side-effects than oral Unsure	 2.00 a (1.13,3.55)					
15c can cause addiction**						
15d goes directly to the lungs**						
Wrong Unsure		3.31 c (1.49,7.35)			2.80c (1.58,4.94) 1.66b (1.14,2.42)	
15e acts faster than those than oral Wrong Unsure				2.28 b (1.25,4.16) 1.84 c (1.30,2.60)		
15f only effective if patient use properly Wrong Unsure			 0.72 a (0.55,0.94)	 1.76 a (1.11,2.79)	 6.59[c] (2.12,20.53)	 0.24a (0.08,0.73)

GP= General Practitioner TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends, TV= Radio and Television

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

** No Source of Information was a significant factor for question 15c and 15d.

Table 4.15 (3a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)–respondent characteristics

	*R^2	Respondent characteristics			
		Age	**Ethicity**	**Education**	**Health care**
16. Two main types of medications: preventers (controllers) & relievers Wrong	4.1c			Pri: 6.42 c (2.55,16.15) Sec: 3.19 b (1.34,7.61)	
17. Quick relievers-salbutamol (Ventolin)					
17a) quickly stop an asthma attack Wrong Unsure	5.2c		Ind: 2.01 a (1.11,3.63) Mal: 2.7 c (1.60,4.55) Ind: 0.68 a (0.48,0.97)		
17b) should only be used when there are symptoms Unsure	4.2c	21-30: 1.76a (1.01,3.07)			
17c) acts by opening up the airways***	2.2c				
17d) should not be used in the long-term to prevent asthma Wrong	1.3c				0.43 a (0.22,0.84)

*R^2 = Pseudo $R^{2,}$, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model. .
[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma. .

* ** No respondent characteristic was a significant factor for question 17b.

Table 4.15 (3a): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)–respondent characteristics

	Source of Information			
	TMP	**Internet**	**Magazines**	**Brochures**
16. Two main types of medications: preventers (controllers) & relievers				
Wrong				2.61 c (1.4,4.86)
17. Quick relievers-salbutamol (Ventolin)				
17a) quickly stop an asthma attack**				
17b) should only be used when there are symptoms				
Wrong	2.06 a (1.13,3.77)			
17c) acts by opening up the airways				
Wrong			3.29 c (1.5,7.21)	
Unsure		0.63 b (0.46,0.88)	1.77 c (1.22,2.57)	
17d) should not be used in the long-term to prevent asthma**				

GP= General Practitioner TMP= Traditional Medicine Practitioners, Fam & Fr = Family and Friends, TV= Radio and Television

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. Indicating that the source of information was "important" was the reference category in each factor.

[a]P<0.05, [b]P<0.01, [c]P<0.005

** No Source of Information was a significant factor for question 17a and 17d.

Table 4.15 (4a & b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)

18. Preventative medications	*R^2	Respondent characteristics			Information source		
		Education	Health care	Specialists	Magazines	Brochures	Talks
18a make the airways less sensitive to triggers and irritants Wrong	1.1a	Pri 2.23a (1.06,4.7)					
18b are only needed when asthma symptoms are frequent							
18c do not stop asthma symptoms quickly Wrong Unsure	3.9c	Pri 2.16c (1.27,3.67) Sec 1.70a(1.11,2.6)			1.84 c (1.25,2.72)		
18d may take a few weeks before the effects are noticed Wrong Unsure	5.2c		2.02a (1.07,3.82)	0.63a (0.43,0.92)		1.94a (1.14,3.29)	1.76 a (1.09,2.84)
18e should be used everyday even when an asthmatic is well Wrong Unsure	7.5c	Pri 2.67c (1.59,4.48) Sec 1.94c (1.31,2.87)				1.73a (1.09,2.76)	
18f can improve asthma and reduce visits to doctors Wrong Unsure	0.8a				1.75 a (1.01,3.03) 1.44 a (1.05,1.98)		

*R^2 = Pseudo R^2, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

*** No respondent characteristic or information source was a significant factor for question 18b using the stepwise procedure.

Table 4.15 (5a & b): Multinomial logistic regression analysis of respondent characteristics and sources of information as factors for Asthma Treatment and Management (ATM)

19 Inhaled steroids	*R^2	Demographics			Information source				
		Education	Health care	Know SO	TMP	Fam & Fr	Internet	TV	Talks
19a can cause stunted growth in children	7.7c								
Wrong		Pri: 0.4 c (0.24,0.68) Sec:0.6 a (0.4,0.91)					0.54 b (0.35,0.84)	3.02 c (1.68,5.43)	0.59 a (0.37,0.92)
Unsure		Pri: 0.38 c (0.24,0.63) Sec: 0.62 a (0.42,0.92)	2.13 a (1.01,4.5)					2.71 c (1.56,4.68)	0.38 c (0.25,0.58)
19b can cause poor memory in children	6.9c								
Wrong			1.99 a (1.01,3.91)	1.51 a (1.04,2.19)	0.65 a (0.45,0.93)		0.61 a (0.39,0.94)	2.53 c (1.45,4.42)	
Unsure		Pri: 0.44 c (0.28,0.71)	3.03 c (1.54,5.96)	1.56 a (1.1,2.22)	0.65 a (0.47,0.92)			2.18 c (1.29,3.68)	0.46 c (0.3,0.7)
19c should not be used for long; patient will depend on it	2.7c								
Wrong			3.93 c (1.96,7.88)						0.59 a (0.37,0.95)
Unsure			4.44 c (2.23,8.84)						0.49 c (0.31,0.78)
19d not the same as used by sportsmen/athletes	1.7c								
Wrong						1.87 a (1.14,3.07)			
Unsure			2.06 a (1.14,3.71)						

*R^2 = Pseudo R^2, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.
[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends, TMP= Traditional Medicine Practitioners.
"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

Table 4.16 (1 a & b): Multinomial logistics regression analysis of demographic and sources of information as factors influencing items related pregnancy and alternative treatments

20. Asthmatic woman	*R^2	Respondent characteristics	Information source	
		Education	Specialists	TMP
20a. Safe to get pregnant? Wrong	5.5c	Pri: 3.58 c (2.18,5.88) Sec: 1.97 c (1.29,3)	2.84 c (1.56,5.16)	0.56 c (0.38,0.83)
20b. Should continue taking their anti-asthma medicine during pregnancy Wrong	4.3c	Pri: 4.11 c (2.26,7.49) Sec: 2.84 c (1.71,4.7)		

*R^2 = Pseudo R^2, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends, TMP= Traditional medicine practitioners.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

Table 4.17 (2 a & b): Multinomial logistics regression analysis of demographic and sources of information as factors influencing items related pregnancy and alternative treatments

21 Effective treatments for asthma?	*R^2	Respondent characteristics						Information source			
		Age	Ethnicity	Education	Health care	Income	Know SO	TMP	Internet	TV	Talks
21a Eating crocodile meat	8.0c										
Yes						1k-2999:2.59a (1.22,5.51)	1.72 c (1.24,2.39)	0.36 c (0.25,0.51)	1.56 a (1.09,2.25)		
Unsure							1.37 a (1.02,1.85)	0.58 c (0.43,0.78)	1.59 b (1.15,2.19)		0.64 a (0.43,0.95)
21b Eating live mice	7.8c										
Yes							1.9 c (1.33,2.69)	0.52 c (0.36,0.75)			
Unsure		16-20: 2.45 b (1.25,4.81)			2.32 a (1.08,4.98)					1.64 a (1.1,2.45)	0.45 c (0.3,0.67)
21c Acupuncture	8.5c										
Yes			Ind:0.44 c (0.27,0.7)	Pri: 0.45 c (0.28,0.73) Sec: 0.54 c (0.37,0.78)				0.36 c (0.25,0.5)			
Unsure				Pri: 0.56 a (0.36,0.88)				0.5 c (0.37,0.69)			

*R^2 = Pseudo R^2, Nagelkerke values displayed were multiplied with 100 to provide the estimated variance explained by the model.

[a]P<0.05, [b]P<0.01, [c]P<0.005 . Know SO= Know someone with asthma, Mal= Malays, Ind= Indians, Oth= Others, Fam & Fr = Family and Friends, TMP=Traditional medicine practitioners.

"Correct" answers were used as the reference category. Only values, and factors which were significant in the stepped: forward entry model are displayed. The reference for each category was female, Age >60 years, Chinese, tertiary education, health care related occupation, family monthly income >SGD5000 and knowing someone with asthma, and indicating the source of information as "important".

4.3.3.6 Asthma patients vs others

Respondents with asthma scored differently from others in 8 out of the 76 questions. Three were related to symptoms (Questions 6d, 8b, and 8c), where a higher percentage of asthma patients answered correctly. In another 2 questions related to inhaled medicines (Question 15a and 15 b), higher percentage of asthma patients got Question 15a wrong, but Question 15d right. A bigger proportion patients answered wrongly for questions on quick relievers (Question 17a and 17b), but correctly on preventers (Question 18a).

Table 4.18: Questions where between asthma patients answered differently

		Asthma (%)	No asthma (%)
6d. lots of coughing, especially at night	Wrong	6	15
	Unsure	37	38
	Correct	58	47
8b. the airways become narrow	Wrong	7	6
	Unsure	31	44
	Correct	63	51
8c. the airways is blocked by thick mucus	Wrong	7	12
	Unsure	31	43
	Correct	63	45
15a. are better than those taken by mouth(orally) like pills or syrups	Wrong	18	12
	Unsure	33	43
	Correct	49	45
15d. goes directly to the lungs	Wrong	6	8
	Unsure	31	42
	Correct	63	50
17a. quickly stop an asthma attack*	Wrong	16	8
	Unsure	31	42
	Correct	53	51
17b. should only be used when there are symptoms	Wrong	14	7
	Unsure	36	43
	Correct	50	50
18a. make the airways less sensitive to triggers and irritants in the environment	Wrong	7	5
	Unsure	34	47
	Correct	60	48

*$P<0.05$, except question 17a, where $p<0.005$

4.3.4 Sources of Health Information

Family doctors had the highest average score (4.3 out of 5 points), followed by specialist doctors (4.14), health brochure or pamphlets (3.67), newspapers (3.58) and pharmacists (3.51). However, 4.4% of respondents thought that family doctors were not an important information source, while almost 1 in 5 thought that nurses and pharmacists were not important.

Demographic characteristics of the respondents influenced their ratings of the importance of various sources of information (Table 4.19). There was also a trend that the less educated respondents rated all information sources with lower importance than more educated respondents (Figure 4.6). Respondents with asthma rank all healthcare professionals including nurses ($p=0.05$), sinsehs and family or friends less importantly, but rank the mass media such as the internet, newspapers, radio or television and other sources such as pamphlets, talks slightly more highly than non-asthmatics.

As shown in the linear regression models, importance of various sources of health information to the respondents influenced their responses to individual items. For example, the rating of importance of television or radio as a source of information was associated with 10 items. The influence of TV and radio were generally positive (8 out of 10 items).

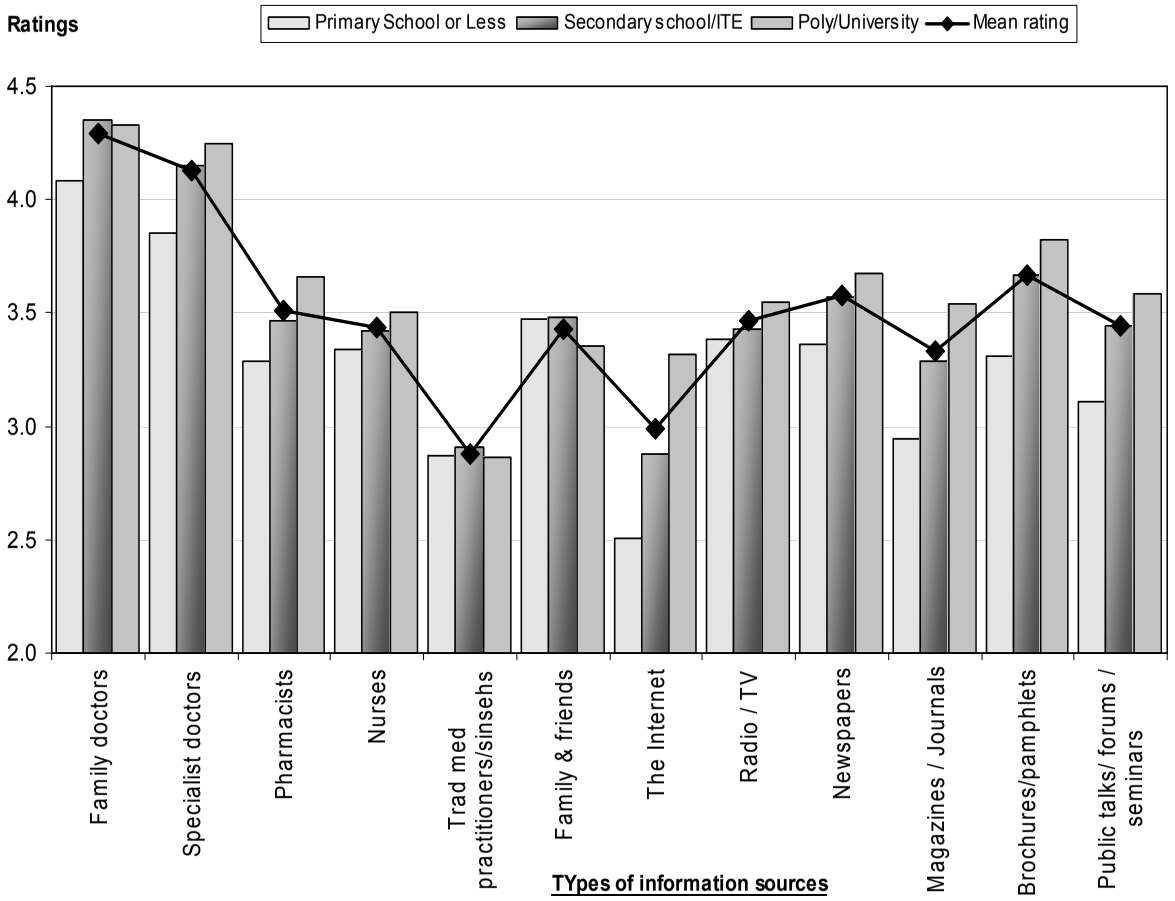
High rating of the importance of TM practitioners (traditional medicine practitioners and sinsehs) as a source of health information were negatively associated with 5 items in the AP and ATM section, and another 3 items about usage of alternative

medicine. The items influenced include increased risk of asthma when other family members have asthma and airway narrowing occurs when asthma attack occurs. Respondent were also more likely to believe that long term usage of inhalers would cause addiction, and agree that cough mixture could be used to treat asthma. It was associated with increased agreement to statements that alternative treatments like TCM, acupuncture, crocodiles' meat and swallowing live mice could cure asthma.

Table 4.19: Demographic factors predicting the importance of various sources of information to respondents

Info Source	Factors predicting the importance to subject
Family doctors	▪ Knowing someone with asthma ▪ Race: Malays place more importance than Chinese (p=0.024)) ▪ Education: Between primary educated and others
Specialist doctors	▪ Knowing someone with asthma ▪ Education: Between primary educated and others
Pharmacists	▪ Education: Tertiary educated group place more importance than primary (p=0.001) and secondary educated group (P=0.026)
Nurses	▪ Having a health care-related occupation
Traditional Medicine	▪ Race: Chinese more than others ▪ Lower family monthly income
Family and friends	▪ Income: Higher in earning < $1000 compared to >$5000 per month (P=0.02) ▪ Having a health care-related occupation ▪ Age
Internet	▪ Age: >60y/o less than all others, 21-30 y/o group highest scores, and significantly more than >50y/o group ▪ Education: Primary educated<secondary<Tertiary educated
Radio/TV **Newspapers** **Magazines or journals** **Health brochures /pamphlets**	▪ Educational level
Seminars/talks	▪ Educational level ▪ Knowing someone with asthma

Figure 4.6: Ratings of importance of various sources of information based on educational levels of respondents



4.4 DISCUSSION

Ideally, a public perception survey should take a probability sampling approach, with stratification in the characteristics which are deemed important in the analysis such as socioeconomic level, age and gender. However, such an approach would be very costly, and will not be within the remit of the research funding available. This limitation in the sampling methods would have implications on the generalisability of the results as the "Singapore population" perception. For example, the ethnic minority groups were over sampled (Malays: 25.1 study-25.1% vs population-13.9%, Indians: 17.9%-study vs 7.9% -population)(Department of Statistics, 2001). The level of education of study respondents also tend to be higher than indicated in the population census (Department of Statistics, 2001). These differences between the study vs the actual population need to be taken into account, when data about the "percentages" of study sample holding an incorrect or correct perception is interpreted. For example, higher levels of indication have been shown in this study to have positive effects in lowering misconceptions. Therefore, when we attempt to extrapolated to the "population", it is possible that the percentages of the population having certain misconceptions could be higher than reported in the study.

In this study, we aimed to obtain information which would be relevant to both public health perspectives and clinician level perspectives, and therefore performed regression analysis on the section scores and also the individual item levels. Bearing in mind that the results would be used in patient and public education efforts, we made a

clear distinction in "wrong" or "misconception" from uncertainty ("unsure") and correct answers.

The ease an individual could "learn" would depend on the existing belief of that individual, as discussed previously in a local study which demonstrated varying effectiveness in "correcting" patients' perception of asthma and its medications (Prabhakaran et al., 2006). Distinguishing these answers allow for different strategy to be applied in addressing the issues. Therefore, scores for both "wrong" and "correct" answers were provided along with the "total score", which would be a useful indicator to monitor the overall knowledge. For example, areas with mostly correct answers show good public understanding and may not need to be emphasized as much as areas where there are lots of uncertainty. In areas with uncertainty, perhaps the strategy would be providing information, whereas for areas with many misconceptions or beliefs which are not consistent or supportive of optimum care, the amount of effort required to change these misconceptions would have been much higher, and these efforts must be targeted at the root of these misconceptions, whether it is a cultural belief or incorrect portrayal of the situation.

More than 60% of the respondents personally knew someone around them who had asthma, and about 30% either had asthma or a family member with asthma. Only 46.3% of questions in the AP and 41.1% of the questions in the ATM were correctly answered. Considering 1 in 5 children and 1 in 20 adults have asthma in Singapore, the general understanding of asthma and its treatments or management could be considered

as still rather poor among the general public (Goh et al., 1996; Ng et al., 1994; Wang et al., 2004).

Generally speaking, respondents who knew someone with asthma scored higher that those who did not know anyone with asthma with respect to asthma treatment and management and also the overall asthma knowledge ($p<0.01$). However, it was rather surprising that respondents who had asthma themselves did not perform better than non-patients ($p=0.06$). In fact they did worse on some individual questions related to the use of inhaled relievers and quick relievers. Nevertheless, similar observation has been reported in another diabetic knowledge study carried out in Singapore (Tham et al., 2004). There were also no differences when the respondents' had family members or relatives with asthma. However, respondents with a friend or colleague with asthma scored significantly better than those without a friend or colleague with asthma.

Subjects with asthma in this study did not know better than subjects without asthma. The proportion of asthmatic subjects in the survey who lacked basic skills for effective asthma management like symptom recognition and medication use was a worrying observation. These observations indicate that both patient and public knowledge is lacking, and education efforts were still insufficient. It is also possible that the Singapore National Asthma Program which was established about two years before the survey was conducted had targeted high risk asthma patients and did not manage to reach out to milder patients.

The observations that respondents who had friends, colleagues or classmates with asthma did better than those who did not, reiterated that there are plenty of room for improving understanding of asthma. It is possible that people tend to notice their friends or colleagues have asthma if the condition was more severe or visible to them. Therefore, they had paid more attention to information about treatment and management of asthma and understood more. It is also possible that asthma patients who managed their asthma well were more willing to share with others about their condition, and therefore, these respondents have benefited from the information passed to them by their friends and colleagues. The observed lack of difference of patients and family members could suggest that they have taken for granted that they knew about asthma, and did not actively seek more information.

Effect of demographic factors and sources of health information had been explored in this study and these could only account partly for the knowledge or perception of asthma and its managements. Demographics and contact with someone with asthma only accounted for 2 to 7.5% of the variances observed. Inclusion of sources of information increased this marginally to a range of 3 to 10% across all the summary scores. Therefore, other unmeasured social cultural or personality factors are likely to account for residual differences in perception of asthma and its management.

Among these socioeconomic factors, education played an important role. Higher education levels were significantly associated with fewer choices of wrong answers for both the asthma perception and its treatment and management sections and congruent with the observations of other studies (Wee et al., 2002; Quek et al., 2002;

Chong et al., 2000). Higher education levels provided the basic skills to needed for "health literacy", which had been defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, 1999). Therefore, their general understanding about health could have prevented them from having misconceptions about a disease or its management.

Ethnicity was thought to be a possible factor for the understanding about asthma and its medication. This study showed that the difference is not in whether a particular ethic group know more or less about asthma. Rather, it is which areas they have more misconceptions or understandings. For example, the Indians seemed to have more misconceptions in the asthma perception section compared to other ethnicities, but at the same time, they also had more number of correct answers which resulted in higher overall scores in the section.

At the item level, the influence of ethnicity is more evident. More Malays and Indians have misconceptions related that poor nutrition, eating too much food and bathing too early or too late in the day was related to causing asthma. Perhaps due to the higher prevalence among Malays and Indians, they did better in items related to symptom identification than the Chinese. Despite that, more of them failed to identify that exercise is a potential trigger. Since about half of Indian respondents in this survey, compared to 2 in 5 for others who thought that using a broom or duster is enough to get rid of triggers from the house, they might need to be targeted at this aspect.

The item with the highest number of correct answer was "Asthmatics can travel without bringing their asthma medications when they are well", where slightly more than 3 in 4 respondents disagreed. This is not consistent with other surveys where more obvious items related to symptoms or monitoring are more usually perform better. This observation could be related to the death of Teresa Teng, a very popular pop singer in Asia. Teresa Teng passed away due to a severe asthma attack during a trip to Thailand in 1995 (Cohen, 1999). The local media had provided tremendous coverage, and tributes still flowed on each of her death anniversary. These could have reinforced that it is important to travel with asthma medications, even when patients are well to the public.

Results from as study on asthma patients and the focus groups (Chapter 3) showed that CAM use is prevalent in among asthma patients, and both Malay and Indian participants in the focus groups reported that the sinseh's treatment worked, or even cured their asthma. The healthcare profession may want to note that about 4 in 10 Chinese, 3 in 10 Malays and 2 in 10 Indians thought that "Traditional Chinese Medicine (TCM) can cure asthma. Another 4 in 10 respondents from each ethnicity were undecided about it. In contrast, the inhaled corticosteroids, the main means to control asthma in Western medicine, were viewed negatively.

Although a majority of respondents knew that asthma need to be treated and could be controlled, most people were not agreeable to long term medication, and either have a negative perception of inhaled corticosteroids or sceptical about its use. The most common misconceptions and uncertainties in this survey were related to these.

Only 4 in 10 disagreed that "All asthmatics only need to take medications when they are not well". For inhaled corticosteroid, less than 20% believed that inhaled steroid would not cause stunted growth or poor memory in children and only 1 in 10 thought that it would be alright to use inhaled steroids long term without worry of dependence. This is less than the number of people who believed in bizarre treatment that crocodile meat (25%) or swallowing life white mice could cure asthma (18%). Therefore, the compliance problems with long term inhaled corticosteroids would be a big challenge. Fears of side effects were main reasons for non-compliance reported in two other local studies (Lim et al., 1996; Prabhakaran et al., 2006). Some participants in the focus groups (Chapter 3) also reported feeling a lot of pressure from "people around them" to discontinue for the fear of side effects. Therefore, more information need to be provided to the public about inhaled corticosteroids to dispel these myths, and build the trust needed to support patients' compliance.

Public health educators may want to start by targeting areas with lots of uncertainties, as these are the areas where people have not made up their minds yet. The top of the list would be items related to the use of inhaled steroids (47.4% to 53.1% unsure answers). Other than stepping up the patient education efforts by health care professionals, the radio and television had also been shown to be information sources which had exerted positive effects in the respondents understanding of asthma symptoms, and their perceptions of inhalers and its side effects. This could be attributed to public educational campaigns held, especially over the Malay and Tamil language channels at around the same time as the survey was conducted. These could play an

important role in closing the gap of health information available between the higher educated and lower educated, and close the health literacy and outcomes gaps.

There are some limitations in the current study. Bias could be introduced when interviewers are allowed to assist the subjects in completing the questionnaire. However, it was a necessary research approach to prevent excluding respondents with lower literacy from taking part. Since adequate training on interview technique was provided, and standard replies to items that might require clarifications were provided to all the interviewers, interviewer bias may have been reduced to an acceptable level

Information related to asthma and its medication is very broad, and covers many areas. While as much information and details about the specific beliefs of the public should be gathered, the benefits of more detailed data had to be balanced against the disadvantages of getting the members of the public to complete long questionnaires. The validity and reliability of the questionnaire could be at risk when the respondent become confused or impatient with the length. Therefore the survey aimed to document *the proportion* of members of the public holding certain beliefs, rather than *why*. For example, it would be interesting to see how much the public believe in avoiding the types of food cited by the parents and patients in the focus group such as chicken and ice cream. Food groups classified according to beliefs of "yin" and "yang" might not have been questioned in sufficient depth enough. For example, oranges might be perceived to start an attack because of its "cooling" properties, rather than allergy related reasons of other food like seafood and bird nest. Similarly peanut might be considered as "heaty". Cold drinks and cold air might have been separated, as these may

involve two different concepts, environmental trigger vs. "cooling" food as a trigger. These are areas which are not within the scope of the current study, and could be considered for future research. Future research could also look into the health seeking behaviours of patients, and study in a more in-dept manner about the relation of wide misconceptions and an individual's health behaviour.

In this study, we sampled respondents from mosques and specific places which are frequented my members of Malay and Indian communities. The ethnic minority were purposely over-represented to ensure sufficient sample size for analysis which involved comparison between ethic groups. The reason for this over-sampling was due to the fact that the proportion of minority ethnic groups in high-risk programmes and hospitalisations due to asthma was higher than population norm (Ng et al., 1999; Ng et al., 2003a; Niti et al., 2003; Teo AH et al., 2003). Further studies of a qualitative nature that seeks to understand the influence of public perception on individual management decisions could be useful in understanding more about these relationships, and its impact on the outcomes of patients from different ethic backgrounds.

4.5 CONCLUSION

The results of this study partially supported the hypothesis outlined earlier. The public's beliefs and knowledge about asthma and its management were only partly explained by socio-demographic factors or sources of information factors. Other unmeasured social cultural or personality factors are likely to account for residual differences in perception

of asthma and its management. Nevertheless, higher levels of education have been shown to generally have a protective effect against misconceptions. However, the results of this study did not support the hypothesis that asthma patients and their family members know more about asthma. This has serious implications in the effectiveness of self-management and health outcomes of the patients.

Various types of information sources also exerted different effects in the individual's beliefs about asthma and medications. Some are associated with positive effects, while others are link to misconceptions about asthma and medications. The mass media such as radio and television, but not newspapers were shown to have mostly positive influence in the public's knowledge. These are important and effective tools that could be used as a wider campaign to improve overall asthma understanding in the community.

The less educated rated all sources of information less importantly than higher educated respondents. This reflected their lower literacy and increased barrier to access health professionals or informational sources. Therefore, this is the group that depend most on healthcare providers, who can play an important role in ensuring important health information are delivered accurately to them in a comprehensible manner.

In conclusion, misconceptions about asthma were still prevalent about members of the public, particularly about the use of long term inhaled corticosteroids. Asthma patients did not show better knowledge than those without asthma. These

observations have negative implications for the effective symptom recognition, and could contribute to the state of under-dianosed, under-treated scenario in Singapore (Lim, 2003). Public education efforts targeted at areas identified as common misconceptions in this study should be considered.

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Chapter 5: Is the Childhood Asthma Questionnaire a good measure of Health-related Quality of Life of Asthmatic Children in Asia? Validation of Childhood Asthma Questionnaire (CAQ-B) Among Asthma Paediatric Patients in Singapore

5.1 INTRODUCTION

Health-related quality of life (HR-QoL) measures provide valuable information on the significance of an intervention from the patient's perspective (Testa & Simonson, 1996c). As outcome measures, HR-QoL measures are complementary to clinical severity or the conventional clinical and laboratory measures as improvements in these latter values do not guarantee that the patient has benefited in daily life from the health interventions provided (Rowe et al., 1993; Nouwen, 1983a; Marks et al., 1993; Juniper et al., 1993; Juniper et al., 1996a; Juniper, 1999a). This is especially true in chronic conditions such as asthma where patients experience exacerbations and remissions (Clark, 2003).

In paediatric patients, a good HR-QoL instrument also serves as a medium where young children can convey their experience of living with an illness instead of relying solely on reports from parents or caregivers. Proxy-reports are not always valid and reliable, and have reported to be more accurate in areas pertaining to physical symptoms rather than in the more subjective areas such as emotions and feelings (Erickson et al., 2002; Guyatt et al., 1997; Juniper et al., 1996b; Marks et al., 1993).

Common chronic childhood conditions like childhood asthma are areas where young patients should be given a chance to express their feelings through HR-QoL instruments that cater to their age or developmental stage. However, HR-QoL measures are still rarely used in children in Asia partly due to the difficulty of obtaining valid, reliable instruments that are developmentally and culturally suitable, and partly

due to the inexperience of the clinical community in using HR-QoL instruments (Bender, 1996; Connolly et al., 1999).

The challenge of using and producing valid and reliable HR-QoL instruments in young children is further complicated by the composition of multi-cultural, multi-ethnic and rapidly developing societies where the official language is frequently different from the language the children speak at home. For example, although English is the common language (lingua franca) for communication in Singapore, less than half of children aged 5-14 years speak English at home (Census of Population Office Department of Statistics, 2000). Therefore, due diligence has to be exercised in choosing an instrument so that it is acceptable and usable, especially in the younger age group. So far, there are very few published studies on cultural adaptation and validation of a paediatric HR-QoL instrument in Asia, with only one published study for asthmatic children in Singapore (Clarke E. et al., 1999).

Asthma is the most common chronic illness among Singaporean children, affecting 1 in 5 children. Any additional information on how this disease impacts on children's quality of life and whether the interventions and treatments provided help would contribute to the management of the disease (Chew et al., 1998; Goh et al., 1996). Hence, there is a need for more research to be performed to provide this information.

The objective of this study was to select a suitable asthma-specific paediatric HR-QoL questionnaire that can be self-administered by most Singaporean children of 7 to 11 years of age, and to conduct a cross-cultural adaptation and validation of the

instrument. The aim was to identify a short and simple questionnaire that would be of clinical use in children with asthma, and adapt it to be culturally appropriate for use in a Singaporean paediatric population. We then investigated whether the adapted questionnaire was valid and reliable and whether the HR-QoL scores obtained correlated with physician- and parent-reported severity.

5.2 METHODS

The cultural adaptation and validation exercise was carried out in two phases. During the first phase of the study, a potential instrument was chosen, tested in a small sample and culturally adapted for local use. For the second phase, a cross-sectional validation of the adapted questionnaire was conducted in a larger sample of patients to determine acceptability, validity, and internal reliability.

5.2.1 Study Design and Patient Selection

This study was conducted in KK Women and Children's Hospital (KKH), Singapore. This 888-bed hospital is the major tertiary referral centre in the area. It has a multiethnic patient pool with various levels of asthma severity and diverse socioeconomic background. The project was approved by the Institutional Review Board/Ethics Committee of KKH and parental consent was obtained for all participating subjects.

Phase one of the study involved inpatients who had earlier been admitted for asthma exacerbation, had recovered and were waiting to be discharged from the hospital.

These patients were referred by their managing respiratory paediatrician and were well enough to do the questionnaires. The patients were selected to represent a range of age, gender and asthma severity. There were no specific requirements on languages spoken, but a conscious effort was taken to include children from different ethnic groups, and from subsidized wards.

Phase two of the study was conducted from June to September 2001 among children and parents/caregivers attending the specialist respiratory outpatient clinic. All asthmatic patients aged 7 to 11 years without other co-morbidities that could potentially significantly affect their HR-QoL were invited to participate. They were identified through medical records and by the attending physician.

5.2.2 Phase I: Questionnaire Selection

During phase one, two asthma-specific paediatric questionnaires were short-listed from a literature review based on the following criteria: (i) designed to be self-administered by the children, (ii) reported acceptable level of reliability and validity, and (iii) rigorous development procedures (Eiser et al., 1999). The Childhood Asthma Questionnaires (CAQs) and Paediatric Asthma Quality of Life Questionnaire (PAQLQ) [were short-listed based on these criteria (Clarke E. et al., 1999; Juniper et al., 1996b).

The PAQLQ was developed and validated in North America for children aged 7 to 17 years. This questionnaire has reported very good reliability and sensitivity in these validations (Guyatt et al., 1997; Juniper et al., 1996b). There are 23 items in 3 domains (symptoms, activity limitations, emotional function). Items were selected using

the clinical impact method. The questionnaire is based on the 7-point Likert scale, takes approximately 10 minutes to complete, and has both an interviewer and standardised version. The questions and response options have been thoroughly tested in many languages. However, the attempt to validate this questionnaire in Singapore reported some problems (Clarke E. et al., 1999).

The CAQs were developed and validated in UK and culturally adapted and validated in Australia with acceptable reliability and validity (French et al., 1994; French et al., 1998). Three versions of the CAQs were developed to take into account the developmental changes from early childhood to adolescence: CAQ-A (4-7 years old), CAQ-B (8-11 years old), and CAQ-C (12-16 years old). CAQ-B and CAQ-C can be self-administered by children, while younger children may require parental assistance to complete the CAQ-A. A few parental questions are incorporated into CAQ-A and CAQ-B as their input can provide complementary and useful information about the children's asthma severity and how asthma has affected the family.

The CAQ-B was most relevant to our patient sample. The CAQ-B (UK) has 23 items in four domains. The four domains are emotions (termed Distress, 6 items), activities (termed Active Quality of Living [AQoL], 7 items), frequency of asthma symptoms (Severity, 6 items) and sedentary pastimes (Passive Quality of Living [PQoL], 4 items). This is a profile-based instrument, where all items in each subscale are added up and the score of each subscale is interpreted separately. Item content for this instrument was derived through focus group work with children and their parents and the subscale structure was also empirically derived through factor analysis. The

questionnaires have been reported to take 15 to 20 minutes to complete, with adult assistance needed for non-readers. Younger children may give their responses by colouring in the "smiley faces", which can increase administration times.

For our study, the questionnaires were pre-tested for ease of application, comprehension and general acceptability. After informed parental consent, ten children selected to represent a range of age, gender and asthma severity were asked to complete the UK or Australian version of CAQ-B and the Paediatric Asthma Quality of Life (PAQLQ) under the direct observation of one of the investigators (CLY). The children and parents were encouraged to ask whenever they had any problems or doubts in filling up the questionnaire. At the end of each session, the children were asked to give their opinions on the general impression of the questionnaire, difficulty in understanding the questions and instructions, what they thought the items meant, how they would have phrased it and whether the activities mentioned in the questionnaires were relevant to them. Attention was paid to the children's ability to understand the questions, grasp the timeframes asked in the questionnaire and understand the choice of answers. Problems raised and duration required to complete the questionnaires were noted.

5.2.3 Cross-cultural adaptation

After evaluating the outcomes and feedback from Phase I, CAQ-B was chosen over PAQLQ. The reasons for this decision will be discussed in the Results section. The CAQ-B items were then reviewed and discussed with a respiratory paediatrician (COM),

other clinicians (one paediatric respiratory specialist and two other paediatricians) at KKH who were in daily contact with asthmatic children and the developer of the CAQ (Dr DJ French) to develop a Singapore version. In this new version, items common to both the UK and Australia version were retained because they were more likely to be "robust" and retain their relevance despite changes in social and cultural background. After that, items in the UK version were chosen if the activities or phrasing were similar to the local context. Although the questionnaire was retained in the English language, changes were made to reflect more closely the Singapore school system, culture, language (rephrasing some items with local terms) and climate based on the feedback obtained from the children who have tried the questionnaire.

Draft copies of the proposed version were shown to paediatricians, children and parents involved in the earlier testing stages so as to get their opinion and further fine-tuning of phrases. The proposed version was approved by Dr DJ French, the developer of the questionnaire. This adapted version will be referred to as the CAQ-B (Singapore version) and was used in Phase II of the study.

5.2.4 Phase II: Cross-sectional validation

When short-listed patients arrived at the clinic, informed parental consent was obtained. The children were then requested to fill in the CAQ-B (Singapore version) before their medical consultation, as recommended in the CAQ manuals (French & Christie, 1995; French, 1996). The investigator went through the instruction section with each child and ensured that the children were able to read and understand the instructions and

questions before leaving them to fill in the questionnaire by themselves. The children were encouraged to fill in the questionnaire on their own without asking for their parents' or other family members' opinion. Based on the instructions, the children could choose to colour in or tick the appropriate boxes and faces of their choice in answering the questionnaire. Careful instructions and encouragement were given to ensure that no child was made to feel uneasy because they were not able to read and any need for clarifications raised by the children were attended to by the investigator at the clinic.

The parents or caregivers were asked to fill in the parental section of the questionnaire after the child completed the questionnaire. Based on clinical features and medications prescribed, the attending physician rated the child's clinical severity and classified each patient into one of the following categories: mild intermittent (infrequent episodic asthma; IFEA); severe intermittent asthma (frequent episodic asthma; FEA); mild persistent asthma (MPA); moderate persistent asthma (mod-PA); or severe persistent asthma (SPA). Because of the small number of patients classified as severe, the mod-PA and SPA categories were combined for analysis (mod-SPA) (MOH Clinical Practice Guidelines 1/2002: 2002).

5.2.5 Method of analysis

Acceptability of the CAQ-B (Singapore version) was determined by the time required to complete the questionnaire, number of children requiring assistance, and the feedback of the children on the phrases, items and their willingness to complete the questionnaire again.

Scores for each item in a subscale were added up. For the "feelings" items, 5 points were given for the happiest face and 1 point was given for the saddest face, and items were scored down the scale for frequency items. For example, a higher Severity score indicates more symptoms while a higher AQoL score indicates better enjoyment of active and physical activities.

Internal reliability (Cronbach's alpha) was assessed under two conditions: (i) when all items in the questionnaire remained essentially the same as the UK and Australia versions (ii) when items that were considered to be irrelevant or vague by the participants were removed from the questionnaire. Coefficients >0.7 are generally regarded as acceptable for psychometric scales. Values should be >0.8 or to be considered good and >0.9 to be considered excellent and suitable for individual patient evaluation. However, it should be noted that these values are often lower for paediatric questionnaires.

To assess the validity of the questionnaire, correlations between the child-reported CAQ-B outcomes and both parents' and physicians' clinical ratings of severity were investigated for all domains. Known-group comparison (severity rated by parents and physicians) was conducted using *a priori* comparisons with ANOVA or independent t-tests.

Initial exploration of the overall questionnaire structure was conducted using principal axis analysis with oblimin rotation and extraction for factors with Eigen values more than 1.0. All statistical analyses were carried out using SPSS11.0 for Windows

(Norusis MJ, 2002). Unless otherwise indicated, the statistical significance level for all tests is set at $p<0.05$.

5.3 RESULTS

Ten children with asthma aged 7 to 14 (mean=10.2) participated in the Phase I of the study. Six of these patients were boys. There were 4 Chinese, 4 Malays and 2 Indians.

5.3.1 Selection of the questionnaire

We found that the CAQs were preferred over PAQLQ, especially in children aged less than 10 years. The younger children had difficulties understanding and differentiating the answer choices or options in the PAQLQ. One common problem was the children's inability to tell the difference between 'quite bothered', 'somewhat bothered', and 'bothered a bit' or 'a good bit of the time', 'some of the time', and 'a little of the time' used in PAQLQ. The children also could not really tell the difference between words such as 'troubled', 'frustrated' and 'angry' or between 'uncomfortable' and 'different or left out'. These feedbacks are similar to those reported in another local study of PAQLQ (Clarke E. et al., 1999).

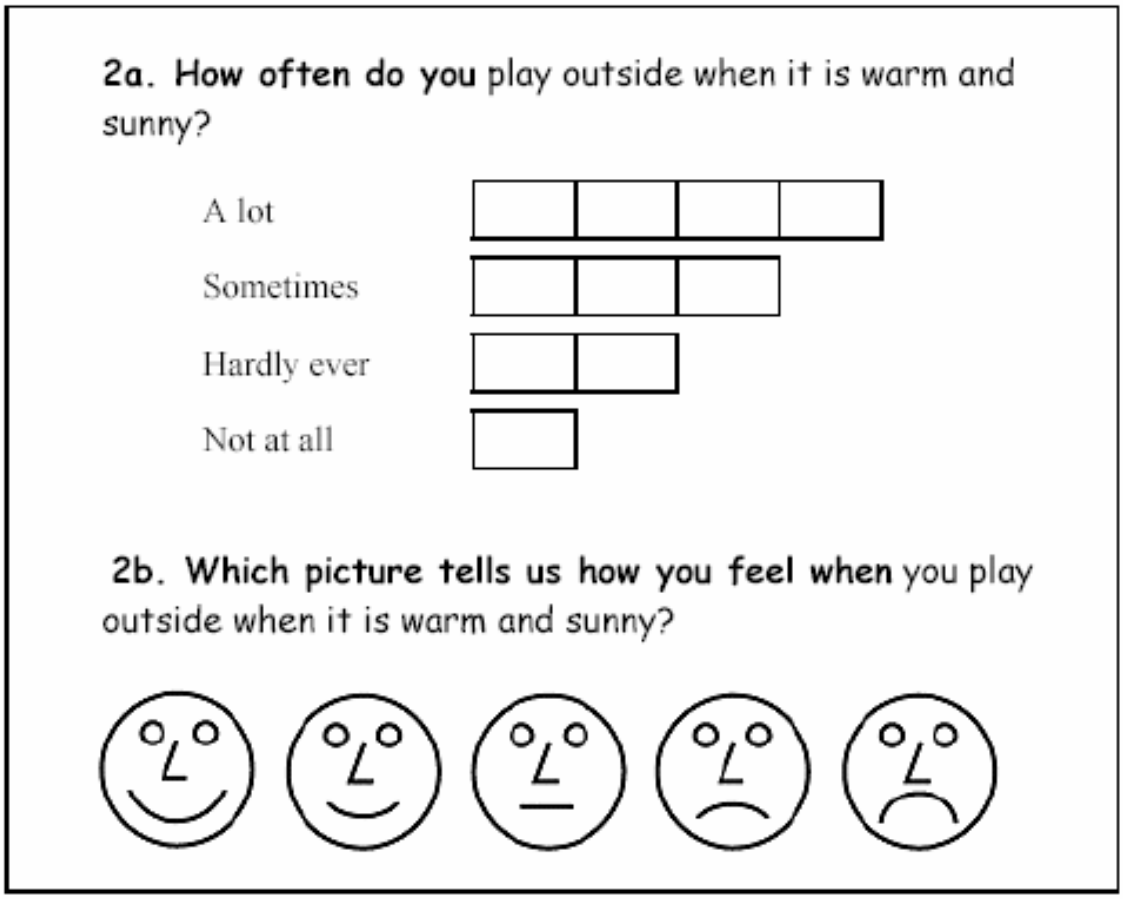
The children found the CAQs "easier", but the instructions too "lengthy" and some of them required some guidance. The sentences and words used in CAQ-B are relatively simple. None of the children reported problem with choosing answer options as the options for how they "feel" are accompanied with smiley or sad faces, while

options for "how often" are accompanied with diagrams representing the frequency (Figure 5.1).

5.3.2 Adaptation of the CAQ-B

Based on the pre-test observations and discussions with clinicians and the original developer of CAQs, several minor adjustments were made to several items to reflect climate, social and cultural differences. For instance, the phrase "playing outside when the weather is cold" in the UK or Australia versions was replaced in the Singapore version with "playing outside when it is a wet day." Other changes made were from "playing inside with toys" to "playing inside with toys or games", "playtime" to "playing" and "physical education" to "PE" to reflect the terms frequently used locally and some children also found "physical education" difficult to read. "Videos" were replaced by "VCDs" as most homes had VCD players rather than video players.

Figure 5.1 An example of the structure of the CAQ-B questionnaire



There were two questions on each page of the booklet (French et al., 1994). There is a leading question, (a) which asks about the frequency of an activity or physical symptoms. This is followed by another question (b), asking about how the child feels while doing or experiencing the activity or physical symptoms. This structure is repeated throughout the questionnaire.

5.3.3 Cross-sectional validation of CAQ-B (Singapore version)

A total of 102 patients completed the CAQ-B (Singapore version). However, only 96 patients (40 girls and 56 boys) with a mean age of 8.7 ± 1.1 years (range: 7-11 years) were included in the analyses. Two were excluded as the diagnosis of asthma was not confirmed. Four had other co-morbidities that could have significantly affected their quality of life: one had self-induced wheeze, one had heart valve problems, one had Attention Deficit Hyperactive Disorder (ADHD), and another boy had to be excluded because of mild mental retardation and related poor concept of time and frequency.

There were more males to females, an expected trend as there are more boys than girls with asthma in this age group. A big majority (79%) of the children in this validation exercise spoke English at home. The implication of this difference will be further discussed in the Discussion section.

Table 5.1: Characteristics of patients involved in the validation of the Childhood Asthma Questionnaire-B (Singaporean version)

Group	N	Age (y)	English speaking (%)	Severity of asthma @			
				IFEA [n (%)]	FEA [n (%)]	MP [n (%)]	Mod-SPA [n (%)]
Male	56	8.7	84	16 (29)	5 (9)	29(52)	6 (11)
Female	40*	8.6	73	13 (33)	5 (13)	18 (45)	4 (10)
Total	96	8.7	79	29 (30)	10(10)	47 (49)	10(10)

@Classification of asthma severity is based on MOH Clinical Practice Guidelines (MOH Clinical Practice Guidelines 1/2002: 2002).
*P<0.05 vs. boys.

5.3.4 Acceptability of the questionnaire

Half of the children completed the questionnaire in 10 minutes (median and mode = 10 minutes, mean = 13 minutes). Most could complete the questionnaires without any help. Only 7 out of the 96 patients (7.3%) needed considerable guidance from either their parents or the investigator. Four of them were in Grade 1 (age 7 years), 2 in Grade 2 (age 8 years) and one in Grade 3 (age 9 years) of primary school.

Seventeen of the younger children chose to colour in their answers and described the process as '*fun*' or '*enjoyable*'. The general comment was the CAQ-B (Singapore version) was '*easy*' and '*quite fun*' to do. However, there were 17 words identified as '*difficult*' by the children (Table 5.2). Some children also commented that the instructions were too lengthy. The comments regarding the wordings are listed in Table 5.3. Eight children were not sure what "wheezing" or "wheezy" meant and needed a description or even a demonstration from the investigators or their parents/caregivers. Some children and their parents refer to it as "whistling" or "noisy breathing" (Cane et al., 2000).

Table 5.2: Wording in the Childhood Asthma Questionnaire B (Singapore version) that may require further modifications based on feedback from patients (n = 96) and parents in the cross-sectional validation

Word list	Number of children affected	Comments
Wheezing/ wheezy	7	No better alternative identified@.
Inhaler	6	May change to 'puffer' or add a picture.
Participate	4	Change to 'take part'
Recently	2	Add 'lately' in brackets
Supposed	3	Rephrase question
Describe	2	Change to 'tell us'
ECA	2	Add 'CCA' in brackets
Swimming	1	Change to 'to swim'
Waking	1	Rephrase question to use 'wake up'
Example	1	No better alternative identified
Asthma	1	No better alternative identified
Watch	1	No better alternative identified
Coughing	1	No better alternative identified
Outside	1	No better alternative identified
tight-chested	1	No better alternative identified
Severity	1	This is in the parental section. Add 'how bad' in brackets.

@ “Whistling breathing” or “noisy breathing” were suggested, but these phrases did not appear to be accepted by all patients.

Table 5.3 : Phrasing and formatting in the Childhood Asthma Questionnaire B (Singapore version) that may require further modifications based on feedback from patients (n = 96) and parents in the cross-sectional validation

Phrasing
1. The children have expressed preference to use 'rainy days' rather than the 'weather is wet'
2. Some schools refer to extracurricular activities (ECAs) as co-curricular activities (CCAs).
3. Question 16a has been noted to be confusing to most children. The original phrasing of 16a) was “How often do you use your inhaler when you are supposed to? It has been suggested to be rephrased as "How often do you need to use your relief inhaler (your medicine) when feeling wheezy?"
Format
1. Some words in the questions need to be highlighted as the children often did not notice them. E.g. Question 9a: “How often do you play games with your class OR participate in ECAs”. The children did not notice the word OR and the younger children (9 years and below) thought that this was not relevant to them as they do not have ECAs.
2. The instructions have been noted to be too lengthy.

5.3.5 Validity and reliability of CAQ-B (Singapore version)

During initial exploration of the questionnaire structure using principal axis analysis with oblimin rotation, twelve factors with Eigen values ≥1.0 were extracted. Some items which were not included as part of the domains in the original questionnaire were found to have high loading values for CAQ-B (Singapore version). The implication of this observation will be further discussed in the Discussion section.

A preliminary estimate of the internal consistency was conducted with the assumption that the items in our questionnaire would fall into the same scales as in the

UK and Australia versions. Internal consistency obtained was slightly lower than UK and Australia (Cronbach's alpha = 0.29-0.76). The Australia version had reported Cronbach's alpha values of 0.62 to 0.90 while the UK version reported values ranging from 0.44 to 0.82 (French et al., 1995; French, 1996; French et al., 1994). However, this increased to comparable levels (Cronbach's alpha =0.57-0.76) when two items that the children had pointed out as having confusing phrasing and one item on reading enjoyment were removed. Reading enjoyment was removed because it was considered likely that this item was affected more by other factors (such as temperament and home environment) than by health. The PQoL Scale improved from 0.29 to 0.57 when the item regarding reading was eliminated (Table 5.4).

Table 5.4: A comparison of the internal validity, ceiling and floor effects of Childhood Asthma Questionnaire-B (Singapore version) before and after (B/A) the item reduction exercise

Domain	n (B/A)	No of items (B/A)	Mean score ± SD		Ceiling effect (%)(B/A)	Floor effect (%)(B/A)	Cronbach's α (B/A)	Items removed in the item reduction
			Before	After				
AQoL	91/96	6/5	24.5±3.6	21.6±2.9	6.6/6.3	0	0.59	3b) Playing outside in rainy days
PQoL	96	4/3	17.5±2.0	13.3±1.8	17.7	0	0.29/0.57	5b) Reading
Distress	90	6	11.9±4.0	11.9±4.0	0	5.6/5.3	0.76	None
Severity	96	7/6	16.2±3.6	14.1±3.5	0	0	0.72/0.76	16a) Use of inhaler

AQoL= Active quality of Living; PQoL= Passive quality of Living; n=number of patients who completed all items on the scale, B/A = Before/After item reduction

5.3.6 Correlation of Scales with Physician and Parent Reported Severity

The AQoL and PQoL domains were significantly correlated (r =0.513, p=0.005) between the (Table 5.5). This indicates that it is possible that these two domains are not distinctly independent.

Physician-rated clinical severity was only significantly correlated to the AQoL domain (r =-0.29, p=0.005). However, parent- or caregiver-rated severity was correlated to three out of four domains: AQoL (r=-0.359, p=0.001), PQoL (r=-0.271, p<0.01) and Severity (r=0.367, p <0.001) (Table 5.5). The Distress domain had no significant correlation with either parent- or physician-rated severity. There was a relatively weak correlation between parent- and physician-rated severity (r=0.22, p<0.05).

Table 5.5: Pearson correlation between the domains CAQ-B (Singapore version), parent-rated severity and physician-rated severity

Scale	Physician-rated severity	AQoL	PQoL	Distress	Severity
AQoL:5 Items	-0.29*** (n = 93)	1 (n = 96)			
PQoL:3 Items	-0.146 (n = 93)	0.513*** (n = 96)	1 (n = 96)		
Distress: 6 Items	-0.034 (n = 87)	0.145 (n = 90)	0.119 (n = 90)	1 (n = 90)	
Severity: 6 Items	0.119 (n = 93)	-0.096 (n = 96)	-0.057 (n = 96)	0.036 (n = 90)	1 (n = 96)
Parent-rated severity	0.22* (n = 92)	-0.359*** (n = 95)	-0.271** (n = 95)	-0.14 (n = 89)	0.367*** (n = 95)

Footnote: *p≤0.05, **p≤0.01, ***p≤0.005
AQOL = Active Quality of Living scale; PQOL= Passive Quality of Living scale

Patients were grouped into severity levels based on the classification of the attending physicians. Scores from each domain in the CAQ-B (Singapore version) were compared between patients with different severity. Orthogonal contrasts with *a prioiri* assumption that HR-QoL will gradually worsen as physician-rated severity increases was conducted. This revealed that children with mod-SPA had significantly lower AQoL than other patients. FEA patients reported significantly higher Severity score than IFEA patients. FEA patients had the highest score on this scale, followed by MPA, Mod-SPA, and IFEA patients (Table 5.6).

When scores were classified based on parent- or caregiver-reported severity, children who were rated by their parents as having mild asthma had significantly better AQoL and Severity scores than those rated as moderate or severe asthma (Table 5.7).

There was no significant difference in the level of distress measured between children with different degrees of asthma severity as rated by their parents/caregivers.

Table 5.6: Comparative scores on subscales of CAQ-B (Singapore version) based on physician classified clinical severity

		N	Mean ± SD	95% CI	Range		p
					Min	Max	
AQoL**	All patients	93	21.6 ± 3.0	20.9-22.2	8	25	
	IFEA	29	22.7 ± 2.3	21.8-23.6	18	25	0.03*
	FEA	10	21.5 ± 2.4	19.8-23.2	17	25	
	MPA	44	21.3 ± 3.3	20.2-22.3	8	25	
	Mod-SPA	10	19.7 ± 2.3	18.0-21.4	17	24	
PQoL	All patients	93	13.3 ± 1.8	13.0-13.7	3	15	
	IFEA	29	13.6 ± 1.6	13.0-14.2	9	15	0.48
	FEA	10	13.9 ± 1.0	13.2-14.6	12	15	
	MPA	44	13.1 ± 2.0	12.5-13.8	3	15	
	Mod-SPA	10	13.0 ± 1.6	11.8-14.2	11	15	
Distress	All patients	87	11.9 ± 4.0	11.0-12.7	6	26	
	IFEA	27	12.1 ± 5.0	10.1-14.0	6	26	0.98
	FEA	10	12.1 ± 3.3	9.8-14.4	6	16	
	MPA	42	11.7 ± 3.8	10.5-12.8	6	21	
	Mod-SPA	8	12.0 ± 2.7	9.7-14.3	9	16	
Severity@	All patients	93	14.1 ± 3.0	13.5-14.7	8	21	
	IFEA	29	13.1 ± 3.1	11.9-14.3	9	20	0.09
	FEA	10	15.4 ± 2.7	13.5-17.3	9	18	
	MPA	44	14.6 ± 2.8	13.7-15.4	8	21	
	Mod-SPA	10	13.4 ± 3.1	11.2-15.6	9	19	

Footnote: * $p<0.05$ using ANOVA analysis between mod-SPA and other patients
** $p=0.04$ between Mod-SPA and other patients, @$p=0.04$ between IFEA and FEA patients based on orthogonal contrast test;
Abbreviation: IFEA= Infrequent episodic asthma, FEA = frequent episodic asthma, MPA = Mild persistent asthma, Mod-SPA= Moderate and severe persistent asthma

Table 5.7: Comparison of scores on subscales of Childhood Asthma Questionnaire-B (Singapore version) based on parent-rated severity

Domain	Score range		Mild[b]	Moderate-Severe[c]	Mean difference	95% CI of Difference	P[d]
	Min	Max					
AQoL	8	25	22.1±2.4	20.04±3.9	2.09	0.3, 3.8	0.02
PQoL	3	15	13.5±1.4	12.8±2.7	0.72	-0.5, 1.9	0.22
Distress	6	26	12.3±4.1	10.9±3.6	1.40	-0.5, 3.3	0.15
Severity	8	21	13.5±2.8	16.0±2.8	-2.52	-3.8, -1.2	<0.001

[@] Data on parent-rated severity were missing for one child. The parent of the patient refused to answer the question regarding severity as he insisted that his child only had "bad persistent cough" (Rated as moderate persistent asthma by physician).

[b] 71 patients were rated by their parents as "mild"

[C] 21 patients were rated as moderate and 3 patients rated as "severe" respectively. "Moderate" and "severe" were combined the analysis due to the small sample size of the "severe" group.

[d] Results from independent t-tests

5.4 DISCUSSION

Both children and parents found the CAQ-B to be a simple and acceptable HR-QoL instrument to children and parents (French et al., 1994; French et al., 1998). From the results of our validation study showed that the adapted version, after minor adjustments and in item reductions, appeared to have acceptable reliability standards such as would be expected from a paediatric self-reported questionnaire. However, caution has to be taken in interpreting these values as further research would be needed to clarify a few issues.

Firstly, further factor analysis with data from a larger population is required, and some items may eventually be moved to another scale. Exploratory factor analysis

of our current set of validation data extracted 12 factors with Eigen values >1. Eigen values reflect how much variation is accounted for in each factor. In factor analysis, the number of distinct factors in a set of data is assumed to be equal to the number of Eigen values >1.0. Some items that were insignificant in the original questionnaire were found to have high communalities for CAQ-B (Singaporean version). More analyses with larger sample sizes are therefore needed to ascertain the significance of this observation.

Of equal importance to the need for further factor analysis may be a need to re-evaluate the weighting of the scores assigned to the items in some of the domains or addition of items in certain domains. This may be necessary in view of the vastly different social and cultural influences between the place of origin of this questionnaire (UK) and Singapore. Whether variations in family and socioeconomic status could impact on the weighting and domains of items also need further study, particularly in children (Sawyer et al., 2000). Some items in this questionnaire are deemed to be *causal items,* but the sample size for the current validation exercise is too small to explore this issue (Fayers PM et al., 2000). Further studies should be conducted to determine the significance of each factor.

Some activities which are important to Singaporean children might not have been included in the CAQ-B (Singapore version). For example, feedback from children and parents who participated in the study showed that quite a few of them worried about the impact of asthma on the children's studies, especially attacks during examination periods. The possibility of getting an asthma attack is a constant threat during the stressful examination periods. On top of that, the main examinations of each academic

year falls in late October to November each year, when the rainy season and surge in flu cases increase the likelihood of asthma exacerbation. In a society like Singapore which places great value in academic achievement, academic performance is very much more important than sports performances to these parents and children. This has been demonstrated by another study conducted by our research group, and may be typical in many Asian societies (Wee et al., 2005). This issue should be further studied to determine if it warrants additions of items about school-work to paint a more complete picture of how asthma affects children in the Asian environment.

Ceiling effects were observed in two scales, the PQoL and AQoL, while floor effects were observed in the Distress scale. Other than the 17.7% in PQoL, the small amount of ceiling effects and floor effects were within expectations due to the wide range of severity and control of asthma in patients who participated in this study.

The small number of questions and type of items asked in the PQoL could have generated the relatively high ceiling effects. As ceiling effects are likely to increase when more patients are well controlled, a greater variety of activities and items might be needed to improve the sensitivity the scale. However, this needs to be investigated in further studies with larger sample size.

Factors other than severity of asthma could have affected the PQoL. PQoL reflects how the patient feels most of the time, and while doing activities such as reading and watching the television. The items in this domain consist of activities that are not physically demanding, and asthma patients are still able to carry them out when

they are unwell. A child's frequency of performing these activities and liking for them is determined more by their interest and the environment or rules at home. As such, this scale is more likely reflective of the patient's general quality of life, and affected by factors such as their personality, and the type of family and social environment they are in. This is consistent with findings from other studies which have reported and discussed the range of factors other than health that influence a person's quality of life (Juniper et al., 1996b; Sawyer et al., 2000; Wan et al., 1999; Wee et al., 2005; Wijnhoven et al., 2003).

One potential threat to generalisability of the results is that a majority of the children in this study spoke English at home. This reflected the generally better socioeconomic status of children attending the specialist clinics; we know from a previous study, children attending such clinics are much more likely to have parents who are better educated, speak English at home and earn more than the patients attending the non-specialist settings (Chapter 2). Therefore, although most children could complete the questionnaires with ease in this study, it has to be borne in mind that this may not be applicable to children in other non-specialist settings such as government-subsidised polyclinics, emergency departments and general practitioners' clinics. This limitation is not only present in this study, but also in other validation studies typically undertaken by specialists in their clinics.

Nevertheless, the concerns about the impact of literacy and socioeconomic status on the generalisability of the current results could at least be partially ameliorated by the use of symbols, such as "smiley faces" and "boxes" to convey the variation in

emotions and frequency (West A, 1995). In an evolving society like Singapore where even the parents and children may not read in the same language or even in societies where low literacy is a common phenomenon, a picture perhaps could convey the nuances and emotions even more accurately than the proverbial thousand words. Based on the fact that only 7% patients required help and more than half of these patients were in the first year of formal school (7 year-olds), CAQ-B (Singapore version) should not be difficult to complete for most children aged 8-11 years old.

The structure of the Singapore version of the CAQ-B is likely to be applicable to Asian societies, particularly city-based school going children. With proper translation, there should not be much difference in the cognitive ability of other Asian children to answer the questionnaires as there are clear diagrams to in the answer choices. For rural communities, more extensive adaptations might be needed, particularly for the AQoL and PQoL domains to ensure the relevancy of the activities in the children's community and culture.

Contrary to initially expectation, physician-rated severity correlated significantly with only the AQoL domain. The lack of significant correlation between physician-rated severity and patient-rated severity may raise questions about the validity of the questionnaire. In spite of this observation, this questionnaire should still be considered valid in reporting HR-QoL, which is from the patients' experiences and perspective.

Firstly, the children's reports correlated strongly with their parent-reported severity in three out of four domains. Secondly, the participants were follow-up patients in a specialist clinic, and it was known that patients in this clinic have relatively well-controlled asthma. Therefore, there may be a discrepancy between the "severity" of symptoms observed by patients and parents and the clinical indices and lung function tests observed by the physician. This is supported by the observation that parent-rated and physician-rated severity had a weak correlation of 0.2 ($p=0.05$), and physician-rated severity correlated with the AQoL domain which reported on more physically demanding activities ($p=0.01$).

This study adds to the body of evidence that factors other than clinical severity of asthma could affect a child's HR-QoL. Results from this study suggest that parents or caregiver's perception of the severity of a young child's asthma was more closely correlated to the child's HR-QoL than clinical diagnosis of the severity as (Table 5.6). Physicians should take heed of parent's descriptions of the severity of their child's asthma, since physicians may often estimate this poorly. In addition, the parent's perception of the severity of the illness may impact on the lifestyle of the child, and this may not be directly related to the underlying severity of the illness. It has been reported that a significant predictor of adjustment difficulties in children with asthma is the mother's estimate of the severity of the condition (Perrin et al., 1989).

In this validation study, the Distress domain that measured the emotions related to having asthma symptoms was not significantly correlated to the severity ratings and other domains. There could be two main reasons.

Firstly, the assumption that the Distress scale correlates to asthma severity may not be valid. This scale had been reported to be psychometrically different from the Severity scale. There were also conflicting reports regarding their correlations (French, 1996). While Langton et al reported relatively stable individual differences and resistance to changes in pharmaceutical trials, Distress had also been reported to correlate to AQOL and PQOL (French et al., 1995; Langton et al., 1995). Secondly, many factors contribute to the distress of having asthma symptoms other than the severity of these symptoms. These include coping and adaptation strategies used by the child, the child and parents' anxiety levels, family functioning and how the parents view and help the children to adapt to asthma (Bender et al., 2000; Kaugars et al., 2004; Markson & Fiese, 2000). As most studies regarding symptoms distress have been related to cancer pains and medical procedures, more studies need to be done to understand the factors affecting asthma symptoms distress in children.

5.5 CONCLUSIONS

A simple adaptation of the CAQs (UK and Australian) was conducted, with minimal changes and the questionnaires structure generally retained. The resulting CAQ-B (Singapore version) which was tested appears to be an easy to use, self-administered questionnaire with a small parental or caregiver completed section that would be suitable for use among asthmatic children in Singapore.

The adapted version showed evidence of validity in terms of strong correlation between most of the domains with parent-rated severity. However, the children's reports did not significantly correlate with physician-rated severity except for

the AQoL domain. The reasons for this observation have been discussed, but more research should be conducted to confirm or refute the relationship between clinical severity, parent's opinion of the severity and the influence of these on the children's quality of life.

The PQoL and AQoL domains involving children's activities have the weaker psychometric properties in this questionnaire. More research is needed to investigate the feasibility of adapting questionnaires across cultures in terms of activities for children. Further studies should be conducted in different countries and cultures to determine and conceptualise domains for paediatric asthma-specific-questionnaire, using both psychometrics and clinometric approaches.

The CAQ-B (Singapore version) has the advantage of offering different perspectives of how a child's life has been affected by asthma. However, as in any HR-QoL instruments, real benefits from administering the questionnaire can only be realised if clinicians and investigators understands the limitations and implications of the results well enough to interpret the information and translate to clinical management strategies.

5.6 ACKNOWLEDGEMENTS

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Chapter 6. Is the Childhood Asthma Questionnaire a good measure of Health-related Quality of Life of Asthmatic Children in Asia? Validation of CAQ-C in Singapore

6.1 INTRODUCTION

Asthma is the most common chronic illness in children and adolescents in Singapore, affecting 1 in every 5 children (Chew et al., 1998). Asthma in older children or teenagers typically begins in early childhood and may get better or worsen in adolescence. The affected patients will have to deal with a disease that is characterized with periods of exacerbations and remissions, with a certain degree of unpredictability (Clark, 2003).

The impact of asthma and its treatment is well-documented to be multidimensional. At this crucial developmental stage, asthma or wheezing have been correlated with activity limitations, lower perceived well-being, more co-morbidities, lower life satisfaction and also an increased display of negative behaviours that could threaten both emotional and social development (Forrest et al., 1997; Zullig et al., 2005). It is unquestionable that this disease would have affected adversely the teenager's quality of life. Therefore, in order to provide better management of the disease, it is of priority to develop valid and reliable methods to quantify the health related quality of life (HR-QoL) impact of asthma and the improvement derived from medical intervention for a disease which affects so many.

HR-QoL has been described as an individual's "subjective perception of the impact of health status, including disease and treatment impact on physical, psychological and social functioning" (Leidy et al., 1999). Therefore it is important to ensure that we are measuring the impact from the patient's point of view. For

paediatrics, it is recommended that HR-QoL ratings should be done by the children themselves, as proxy-reports have been reported to be less accurate in subjective areas such as emotions and feelings than in areas more objective areas pertaining to physical symptoms and functioning (Eiser et al., 2001; Guyatt et al., 1997; Juniper et al., 1996b; Marks et al., 1993).

Conducting cross-cultural adaptation and translation on other developed instruments is a practical and economical way to obtain valid and reliable instruments. Other than these practical advantages, this strategy also allows cross-country comparison of the data obtained, and is widely practiced for adult HR-QoL questionnaires. Many paediatric HR-QoL instruments have been reported to be translated and adapted to various degrees of success of maintaining the validity and reliability of its original version (Wee et al., 2005; Ma et al., 2006; Schmidt et al., 2006).

In certain countries and cultures, a teenager's life may revolve around taking care of younger siblings or even their own children; whereas school life, friends, academic and athletic performance may be of concern to teenagers in another part of the world. Therefore, the challenge of paediatric and adolescent HR-QoL adaptation is in obtaining a valid and reliable local version of a questionnaire, while maintaining conceptual equivalence.

The objective of this study was to select a suitable asthma specific paediatric HR-QoL questionnaire developed in the western culture that could be easily completed by most Singaporean teenagers, and to conduct a cross-cultural adaptation and

validation of the instrument in Singapore. This should be a short and simple questionnaire which could be of clinical use in teenagers with asthma. The validation of such an instrument in Singapore, which is probably one of the most westernized among the Asian countries but maintaining most Asian values, would be a promising first step for the use of the instrument in other Asian environment. The instrument chosen for our study was the Childhood Asthma Questionnaire (CAQ-C). In a previous study, we have reported the reason for the selection of the instrument and the results of the cultural adaptation and validation of the Childhood Asthma Questionnaire (CAQ-B) (Chapter 5). In the present study, we would report the results obtained with the Childhood Asthma Questionnaire (CAQ-C) for use among Asian adolescents.

6.2 METHODS

6.2.1 Participants

The study was conducted in KK Women and Children's Hospital (KKH), a major hospital in Singapore, and was approved by the Institutional Review Board of the hospital. All asthmatic patients aged 11 (or studying in Grade 5 but not reaching their 11th birthday yet) to 17 years, without other co-morbidities that significantly affect their HR-QoL were invited to participate. These patients were identified through medical records and by the attending physician. Diagnoses were made by a paediatric respiratory specialist (COM).

6.2.2 Measures

The CAQs were developed and validated in UK and culturally adapted and validated in Australia with acceptable reliability and validity (French et al., 1994; French et al., 1998). Three versions of CAQs were developed to take into account the developmental changes from early childhood to adolescence: CAQ-A (4-7 years old), CAQ-B (8-11 years old), and CAQ-C (11-16 years old). Except for CAQ-A where younger children may require parental assistance, CAQ-B and CAQ-C could be self-administered by the children.

The CAQ-C (UK) has 41 items in 5 domains. The 5 domains were emotions (Distress, 12 items) and activities (Active Quality of Living, AQoL, 8 items) frequency of asthma symptoms (Severity, 9 items), activities associated with the teenage years (Teenage Quality of Living, TQoL, 7 items) and frequency or distress caused by triggers and environmental factors (Reactivity, 5 items). This is a profile based instrument, where all items in each subscale are added up and the score of each subscale are interpreted separately. Item content for this instrument was derived through focus group work with children and their parents and the subscale structure was also empirically derived through factor analysis. The questionnaires were reported to take 10 to 20 minutes to complete (French et al., 1995; French, 1996).

The CAQ-C were scored as recommended in the UK and Australia manuals (French et al., 1995; French, 1996). The items in the Distress scales were given reversed scores and summed: very happy - 1, quite happy - 2, neutral - 3, quite sad - 4, very sad -

5. A low score indicated low distress while a high score indicated high distress. Severity, AQoL and TQoL items were already scored in the appropriate direction and are summed, so that high scores indicate frequent symptoms, enjoyment of games or sports and activities associated with the teenage years respectively. The Reactivity scale also required the reversal of items such that a low score indicated low reactivity and a high score indicated high reactivity.

A cross-cultural adaptation of the CAQ-C for Singapore was conducted. The cultural adaptation process was as follows. Opinions about the questionnaire were solicited as part of structured interviews with 10 asthmatic inpatients on their day of discharge. They were questioned regarding their ability to understand the questions, relevance of items, structure of the questionnaire and also the phrasing of items. The questionnaires items were reviewed and discussed with a respiratory paediatrician (COM), other respiratory clinicians at KKH who were in daily contact with asthma children as well as the developer of CAQ (Dr. DJ French) to propose a Singapore version based on the children's feedback.

In this newly proposed Singapore version, we retained the items common to both the UK and Australia versions. These items were more likely to be "robust" and retained their relevance despite changes in social and cultural background. Australia's weather is also closer to the tropical Singapore weather. After that, these items were re-examined carefully. Items in the UK version were chosen if the activities or phrasing were more similar to the local context. Changes were made to reflect more closely the Singapore school system, culture, language (minor rephrasing of some items with local

terms) and climate based on the feedback we had from the children who have tried the questionnaire

Changes adopted by the proposed version included the followings. Items on going out when the weather is cold was removed and the other two items on going out in warm or hot weather was rephrased as "going out when the weather is fine and weather is wet". The items on smoking were also removed as most teenagers at this age will not admit to smoking, both due to strong taboo and the fact that it is illegal for teenagers under age of 18 to buy cigarettes in Singapore. As reported in the CAQ-B, these changes were made to reflect the local situations. The proposed version was approved by Dr DJ French, the developer of the original questionnaire. This version will be referred to as CAQ-C (Singapore version) in this paper. This questionnaire contains 39 items, compared to 46 items in the UK and 40 items in the Australian version. More information regarding the validation procedures and HR-QoL instrument selection and cross-cultural adaptations have been previously reported (Chapter 5).

6.2.3 Statistical Analysis

ANOVA tests were employed when comparing three groups of patients or more; MannWhitney, Wilcoxon and t-tests when comparing two groups of patients. Cronbach's alpha was reported for internal consistency of the scale in item reduction. Pearson's correlation coefficients were reported for correlations. These are described in the relevant sections below. For all the tests, a significance level of 0.05 was used,

unless otherwise indicated. All data processing and analyses were performed using Statistical Analysis System (SPSS) software (version 11.0) (Norusis MJ, 2002).

6.2.4 Analysis of Psychometric properties

Psychometric evaluations were conducted to assess the validity of the adapted questionnaire, and to understand the structure better.

Construct validity. There were discrepancies of the domain structures between the UK and Australia versions. Five items in CAQ-C were unique to the UK version and 4 items were only found in the Australian version. Apart from the items which were unique to each country, ten items "drifted" into different domains in the Australian version compared to the original UK version. This "drift" was particularly apparent in these domains; TQoL (4 out of 5 items) and AQoL (5 out of 8 items) (please refer to Table 6.1). Taking into consideration the item drift which occurred and the adaptation of some items to ones which are relevant to the Singapore context, we performed exploratory factor analysis (EFA) using Principle Component Analysis (PCA) with Varimax rotation to determine the scale structure of this adapted questionnaire.

Internal consistency: The internal consistency was estimated to assess the extent to which individual items are consistent with each other. This was conducted on all possible versions of the '*postulated domains'*. Item reductions were then performed to see how removal and addition of these items affect the overall internal consistency of the domain. Cronbach's alpha coefficient value of at least 0.70 has been recommended if the measure is to be considered reliable, above 0.8 to be considered good and 0.9 to

be considered excellent and suitable for individual patient evaluation. However, reliability coefficients are affected by the number of items within a scale (Nunnaly JC et al., 1994). Alpha coefficients will tend to be smaller in scales with fewer items, and this would be considered when interpreting scales with different number of items.

Known-groups validity: After determining the scale structure, correlation between physician rated severity and the domains of the CAQ-C (Singapore) were investigated for all domains (MOH Clinical Practice Guidelines 1/2002: 2002). Known group comparison was conducted using *a priori* comparisons with ANOVA or independent t-tests.

The above analyses were performed to as a preliminary evaluation of the psychometric properties of the adapted CAQ-C. All these tests were conducted using the SPSS software (version 11.0) (Norusis MJ, 2002).

Table 6.1: Items which drifted to another domain upon cultural adaptation from UK to Australia (French et al., 1995; French, 1996).

Item	UK's domain	Aust's Domain
(a) often …swimming	AQoL	TQoL
(b) feel…swimming	AQoL	TQoL
(a) often…go partying	TQoL	AQoL
(b) feel…go partying	TQoL	AQoL
(a) often…dance at parties	TQoL	AQoL
(b) feel…dance at parties	TQoL	AQoL
(a) often…school PE or sports	AQoL	Severity
(a) often…fine weather	AQoL	TQoL
(b) feel…fine weather	AQoL	TQoL
Feel…forgot inhaler	Reactivity	Distress

Some items in the questionnaires have two parts. Part (a) refers to the frequency of an activity or experience. For example: *How often* do you go swimming? Part (b) refers to

the feelings of the respondent when they carry out an activity or going through certain experiences. For example: *How do you feel* when you go swimming?

6.3 RESULTS

6.3.1 Demographic and Clinical Characteristics of the Sample

In this study, 99 patients completed the proposed Singapore CAQ-C. Baseline socio-demographic data and clinical severity of the sample are shown in Table 1. The majority of the sample (58%) was boys and the mean age (± SD) was 12.8 ± 1.6 years. The majority of patients (76%) spoke English at home, and 72% were Chinese.

Table 6.2: Participants in the validation exercise

				Severity[@]				
Group	**N**	**Age (year)**	**English speaking (%)[#]**	**IFEA (%)**	**FEA**	**MPA**	**Mod-PA**	**SPA**
Girl	41	13.0 ±1.8	68	12 (30)	3 (7)	18 (44)	6 (15)	2 (5)
Boy	58	12.7±1.6	81	17 (29)	3 (5)	18 (31)	15 (26)	5 (9)
Total	99	12.8±1.6	76	29 (29)	6 (6)	36 (36)	21 (21)	7 (7)

Participants come families which converse mainly in English at home. At the time of study, less than half of children aged 5-15 years old speak English at home (Census of Population Office Department of Statistics, 2000).

6.3.2 Acceptability, completion rates and duration to complete

All, except for 2 boys (aged 11 and 12 respectively) who needed some help to understand the instructions, could complete the questionnaires independently without help. The patients found the questionnaire “ok” and commented that the items were

relevant. More than three quarter of the patients finished the questionnaire in 10 minutes or less (mean=8.8, median= 9 minutes).

Seventy-five patients had no missing data. Eight of the patients had 1-2 items missing, 6 had 3-4 items missing while another 8 had 5 or more items missing. The average amount of missing data per patient was 1.0 ± 2.1 items.

Some questions had more missing data than others. Out of the 39 questions, 12 had missing data., with 87% of the missing data contributed from the items in second section regarding how the patient felt when experiencing asthma symptoms, i.e., the Distress Scale (Table 6.3). All the missing answers in this section were contributed by patients who had answered that they never had any of these particular symptoms in the past few weeks. Among patients who had answered "Never *or* Not at all" to an item about frequency of asthma related symptom [Part (a)], 16% to 46% did not answer the corresponding "Feeling" [Part (b)] section of the question.

Other items which contributed to missing values were items on how the patients felt about having to carry inhalers (2%), how they felt when they have forgotten their inhaler (3%), how they felt about having asthma (1%), how bad they thought their asthma have been (2%) and how well they thought their medicine was working (1%).

The answers provided by the respondents covered the full range of the response options for most items. One exception was for the items related to going out when it is raining; only 3 out of 5 response options were used. Items for frequency of asthma symptoms usually had no answers for the highest level (having a certain symptom, "*All*

of the time"). The response option "*Great, I really like it"* had no response for most items related to "feeling" about having asthma-related symptoms.

Table 6.3: The items in the questionnaire which had missing data

Item	Number of patients who answered "never, or not at all" to the corresponding section (a)	Number of patients with missing data, (n= 99)	Percentage of missing data contributed by item[@]
Q8B (…feel about getting wheezy or tight-chested)	26	12	12.6
Q9B (…feel about coughing?)	19	3	3.2
Q11B (…feel about waking at night with asthma?)	58	20	21.1
Q12B (…feel about missing school because of asthma)	56	19	20.0
Q13B (…feel about missing playing sport at school because of your asthma?)	42	16	16.8
Q10B (…feel about having asthma attacks?)	42	12	12.6
Q14B (… feel about getting asthma when you run?)	16	4	4.2
Distress scale x items (Total)		86	90.5
Other items not from Distress scale		9	9.5
All items		95	100.0

[@]"Percentage of missing data contributed by item" was calculated as "number of patients with missing data" for a particular item ÷ Total number of missing item in the study.

6.3.3 Psychometric Properties

6.3.3.1 Construct validity

Exploratory factor analysis (PCA) was performed on the data on samples without missing data. Thirteen factors with Eigen values of more than one were extracted. As a rule of thumb, the number of factors is a scale is equal to the number of factors with Eigen value of one and above (Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy for this analysis was 0.515. A value of 0.5 and above was considered as miserable, and a value of 0.6 and above considered as mediocre (Kaiser, 1974).

6.3.3.2 Reliability: Internal consistency

Based on the psychometric structure in the UK and Australia versions, the Cronbach's alpha reliability coefficient of each domain was analyzed.

There were two alternative postulated versions for both Distress and AQoL scale. These alternative versions were analyzed to take into account items which had drifted from one domain to another in when adapted from UK to Australia. Item number 13(b) "…feels about missing sports because of your asthma" was in the AQoL domain of the Australian version, but not in UK version. It was tested both as the AQoL domain and the Distress scale, as this item was also significantly correlated with items in the postulated Distress scale. Items that drifted from one domain to another were tested in both domains. For example, the item "…feel about forgetting your inhalers…" which had drifted from the Distress Scale in the UK version to Reactivity scale in the

Australian version and was postulated to be in the Singapore's Reactivity scale, but was also tested in the Distress scales for this item.

When compared with the validation studies that were used to determine the internal consistency for the UK and Australian versions of CAQ-C, the sample size for our study was smaller, and the mean age of our study subjects was younger than the British sample but older than the Australian sample (French et al., 1994; French et al., 1998; French DJ & Christie, 1995; French DJ, 1996). A comparison of the number of items of CAQ-C (Singapore version) with the UK and Australian versions, before and after the item reduction exercise is shown (Table 6.6).

6.3.3.3 Known group validity

In this analysis, none of the domains were correlated to physician rated severity. There were also no statistically differences in domain scores based on this categorization method.

Table 6.4: Pre-rotation principal component analysis extracted 13 factors with Eigen values of more than 1.

	Initial Eigen values			Rotation sum of squared loadings		
Factor	Eigen value	% of variance	Cumulative % of variance explained	Eigen value	% of variance	Cumulative % of variance explained
1	5.2	13.3	13.3	3.7	9.4	9.4
2	4.0	10.3	23.6	3.0	7.7	17.1
3	2.9	7.5	31.1	2.6	6.6	23.7
4	2.5	6.4	37.5	2.3	5.9	29.6
5	2.3	6.0	43.5	2.1	5.5	35.0
6	1.9	4.8	48.2	2.1	5.4	40.4
7	1.8	4.7	52.9	2.0	5.2	45.6
8	1.5	3.9	56.9	2.0	5.2	50.8
9	1.4	3.7	60.6	2.0	5.2	55.9
10	1.4	3.5	64.0	1.9	4.8	60.7
11	1.3	3.2	67.2	1.7	4.4	65.1
12	1.2	3.1	70.3	1.7	4.3	69.4
13	**1.0**	**2.6**	**72.9**	1.4	3.5	72.9
14	0.9	2.4	75.3			

Figure 6.1: Scree plot of the exploratory factor analysis using principal component analysis (PCA)

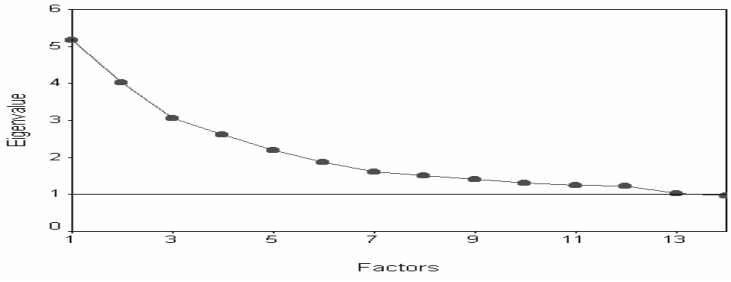

Table 6.5: Varimax rotated component matrix obtained from performing principal component analysis

Rotated Component Matrix	Components												
	1	2	3	4	5	6	7	8	9	10	11	12	13
often...woken up at night with asthma	79					22			13			-17	
often...asthma attacks	76		-13		27				12		14		
often... wheezy of tight chested	74		-19			14				16	24	20	
often... coughed	70				-15	16		-14	-19	-14	-20		10
feel...waking up at night with asthma		78		12	12	-14		16				16	21
feel... running make you cough or wheeze	13	77	17	-11				-10		14			-23
feel.. about having asthma		75		-17	14						20		12
feel...asthma attacks	-18	62			-20	34	-13	-12					
feel..coughed		51			19	18		26		25	41	12	
feel... sports of games outside			81	-15		-11	15		24				
feel... PE or gym indoors			78		12	-13					17		12
often ,,, sports or games outside	-30		62	22	16			43	-14	16		-10	
feel... missed playing sport		27	56	-12	-11		-28			19	19	18	31
feel.. go out when the weather is rainy	19			80	13				-15				15
often.. go out when the weather is rainy	-14		15	65	29	20		-35			18	-16	
feel... go out with friends		13	23	-65	33				-31		-20		
feel... making new friends			26	-43			29	-12			-22	38	34
feel... swimming pool		10	13		84				20	-14		14	
often.. swimming pool				25	74	-19		16	-16			-11	11
often... missed school	38	17		10	-15	70		11				-19	
often... missed playing sport	38		-37			62			-19			19	-13
often... running make you cough or wheeze	34	-24	-13			57		-17	11	12		27	29
often.. missed school because you are not feeling well	49		-14		11	55		16	33				-24
.. often books and magazines							87			14			
feel.. books and magazines				-16		10	86			-12			
often.. go out when the weather is fine			10					86	10			13	
often.. go out with friends	19			-30	35			49	-38	22	-14	-17	
often... PE or gym indoors	-18		13	24	22			44		-19	44	-16	
feel.. go out when the weather is fine	19	16	16				27		78		-14		
how well your medicine is working	35		-13		-14		31		-57	14	-24		
often.. do you get coughs and colds	30	-15		17		26		-26	46	13		17	14
feel.. telling people that you have asthma					-14		11			80			
feel...about having to carry inhaler	-12	29	16		13			25	-14	57	-12	32	
feel.. when parents or teachers fuss over you	17	19		-28			-18		29	49		36	
feel... wheezy of tight chested	-20	32	12		30	29	-18	-22	22	40	14		
feel...finding that you have forgotten your inhaler	14		18				12	-14			73	-12	
how bad is your asthma	37	20		21						-28	52	20	
feel.. about having to avoid things that make you cough or wheeze		14							12	12		84	-20
feel... missed school		16	11					13				-21	83
Extraction method: Principal Component Analysis., rotation method: Varimax with Kaiser normalization.													

Table 6.6: A comparison of the internal validity, and study sample between the UK, Australia and Singapore version (both postulated version and after item reduction)

	UK Version		**Australia Version**		**Singapore** (Postulated) [@]		**Singapore** (after item reduction)	
Domain	No of items	Cronbach's **α**	No of items	Cronbach's **α**	No of items	Cronbach's **α**	No of items	Cronbach's **α**
Severity, SEV	9	0.78	10	0.83	12	0.85	8	0.85
Distress, DIS	12	0.78	11	0.79	11	0.72	10	0.74
					13[#]	0.72	10	0.77
AQoL	8	0.75	8	0.76	9*	0.64	4	0.74
					8	0.65	4	0.71
TQoL	7	0.5	6	0.71	7	0.52	3	0.65
Reactivity	5	0.8	5	0.52	3	0.25	3	0.25
	41		40		41		28	
Sample size	229		120		99		99	
Mean age (SD)	14.3		11.8		12.8(1.6)		12.8(1.6)	

Including item no 13(b) "…feel about missing sports because of your asthma" and item No 16(b) "…feel about forgetting your inhalers…"

* Including item no 13(b) "…feel about missing sports because of your asthma"

6.4 DISCUSSION

Establishing the psychometric properties of a HR-QoL measure is an essential part of its development. If such measures are to become useful tools in clinical and research settings, they must have good reliability and validity, and be responsive to changes. Besides maintaining these qualities when adapting a HR-QoL questionnaire into another culture, language or society, it is also important that the conceptual equality is maintained.

The aforementioned difficulties are amplified when adapting HR-QoL instruments for use in teenagers and adolescents. The difficulty of measuring QoL in teenagers and children has been described as akin to "trying to measure a 'moving target'" i.e., the change of the internal "targets" due to the development process (which could be viewed as a type of response shift). When doing a cross-cultural adaptation for an instrument meant for teenagers, we also have to bear in mind the possibility that the development process may be different across various cultures and countries due to a difference in the education system and socio-cultural norms. Children from different cultures grow up at different rates and different ways. For example, going to school may be an everyday activity in one society but a sheer luxury in another. In contrast, for adults, regardless of where they live, their components of their QoL can more easily be 'functionally' categorized into different domains: work; social; emotional and mental health; physical fitness and satisfaction with their functions etc. Hence, developers of children and adolescents' quality of life are faced with the challenging task of trying to classify a growing child's development processes as well.

The findings of this study also reinforced the need to conduct factor analysis in various samples when determining the construct validity of a scale, particularly when cross-cultural adaptation had been conducted. When the results of the Australia, UK and Singapore versions were compared, there were some noticeable "drift" of items between domains, such as between AQoL and TQoL, and between Distress and AQoL (French et al., 1994). Examining the type of items involved tells us this is possible, as activities like playing sports may be part and parcel of a teenager's life in some societies, and not merely an 'active' activity. Non-participation may mean deprivation from participating in a normal activity and come with a risk of social exclusion. And yet in another society or culture, sports participation may be seen as part of an active lifestyle; a choice.

Conceptually, to what extent these two domains are distinctive enough from each other to be considered as two domains also need to be considered. There are many overlaps between these two social/functional roles, and these overlaps could have been augmented or downplayed by cultural and social expectations. Unlike HR-QoL research in adults, there is still a lack of information about the types of domains which exist in a "typical" disease specific instrument for teenagers. Should there be distinctive social (equivalent to TQoL), functional or "active" scales? Will items shift from one domain to another when the cultural borders are crossed? Research to determine the typical domains which make-up a disease specific instrument for teenagers, and whether these domains will remain robust across cultures are still lacking and as far as we know, had never been reported in an Asian context.

Wee et al. conducted focus group studies among children and adolescents in Singapore, and reported that although there seemed to be a "universal" concept of HR-QoL in terms of having major components like physical, psychological and social health, the components which made up these domains could be different (Wee et al., 2006). This could be related to the drift of items to different domains when adapted to different countries.

For example, the school emerged as a very important environment for children and adolescence in all the HR-QoL components, i.e. physical, social and psychological health, both when ill and healthy. This is not surprising in a society such as Singapore where meritocracy and scholarly pursuits were emphasized and encouraged. A major repercussion of being ill is falling behind or increase in school work due to absence, and falling behind academically. The children and adolescents reported that not being physically healthy or not getting enough sleep could affect their ability to "concentrate". Many of the activities which the children "enjoy" doing, or consider as "fun" were done in school. Physical health were mainly related to getting sufficient sleep, maintaining a "healthy lifestyle" and doing activities like skipping, jogging, swimming and cycling. In contrast, in a society like Australia, sports may not only play a role in the physical health, but also contribute to social and psychological domains of a teenager's lifestyle

Developmental changes could also affect the relevance and make up of components in each domain. The adolescents were more affected by school work and examinations. Their social circles also enlarge as they grow up, and they have more

variety in social activities, like watching movies. Teenagers also seemed to be more concerned about body image, others' opinions and their "future".

Overall, the present version of the questionnaire is fast and simple to complete, and acceptable to most children in this study. This would be an important practical consideration if an instrument needs to be used repeatedly in a clinical setting. However, missing answers from certain items seems to be a problem for the section regarding how the patients felt about experiencing certain asthma symptoms.

One limitation in this study lies in the sample size and the types of patients who participated in the study. The ideal sample size for factor analysis is debated with opinions ranging from at least 100 subjects to least equivalent to five (some have suggested 10) subjects per item included in the analysis (Fayers PM et al., 2000). The sample size of this study limits the generalisability of the factor analysis results of this study. Furthermore, the questionnaire may contain some causal indicator items. The presence of causal indicator items had been debated as unsuitable for factor analysis (Fayers & Hand, 1997), and it has been reported that items which were important to patients would have been dropped if factor analysis was used on its own in scale development (Juniper et al., 1997b). Therefore the results could serve as preliminary data, and the prototype where future HR-QoL instruments for asthmatic children could be built on.

As reported in our study with CAQ-B (Chapter 4), the second limitation is that our participants were from a specialist clinic. Many of them had very well-

controlled asthma and had not experienced certain symptoms in the "past few weeks". This might have contributed to the lack of correlation between physician-rated severity and the domains, and also the missing answers from the Distress scale. In our analysis, the domains in CAQ-C were not significantly correlated with physician-rated severity, nor showed discriminative power for the different levels of severity. This is consistent with the findings in the CAQ-B study, where physician rated-severity was only correlated with the AQOL domain while parent-rated asthma severity was significantly correlated with three out of four domains in the instrument. In addition, the NAEPP guidelines, which is very similar to the Singapore's MOH guidelines was reported to be not reflective of the asthma burdens for children younger than 16 years old (Kwok et al., 2006). Besides, having patients whose asthma are well controlled and managed could have partly exacerbated this lack of correlation.

One area which may be explored if there was sufficient size was validity and relevance of the instrument for different ages groups. With a larger sample size, various age groups, particularly the younger groups and the older patients may be excluded from the analysis to see whether this improved the validity of the questionnaire. As Asians may mature at a different rate, there may be changes in validity and also the drift of items from one domain to another.

As the time frame of symptom frequency used in this questionnaire was "the last few weeks", "Never" was a rather common choice of answer with respect to frequency of symptoms (average was 37% per item, ranging from 16% for wheezing or having attack when running to 58% in waking up at night with asthma). This could have

contributed to missing answers in Distress domain on the questionnaire. All the missing answers regarding "feel about" having a particular symptom were contributed by participants who had answered "never" to the corresponding frequency question. It is possible that among these patients, some might not recall any experience of these symptoms and therefore unable to tell how it feels like. Therefore, they were not able to answer the part (b), i.e., the "feeling" part of the question.

On the other hand, there are patients who might have remembered how it felt like to have these severe symptoms, although "never" experienced it "recently". Among the patients who could remember the experience, some might no longer be bothered by the experience or worried about a recurrence.

It is clear there could be a big difference in terms of emotional well-being among patients who had never had any of these bad experiences or not bothered by them, compared to those who were still traumatized by the previous episodes or had to take active measures to prevent it. Therefore, the timeframe that was addressed by the questionnaire and the scoring system for the Distress scale need to be further studied. Research from the cognitive and childhood development is needed to determine what would be the optimal time frames to address these questions, and also provide some answers on whether there are any differences in the length of time frames that could be recalled accurately by children across various ages.

The potential of CAQ-C lies mainly in the simplicity of its structure, and acceptability to teenagers. Further factor analyses to determine the domains and other

psychometric properties could be examined in a larger study. Nevertheless, findings from this study offer support for the conceptual framework of the instrument and supports emerging studies regarding the complementary nature of QOL measurement to the clinical severity rating of asthma.

In the current validation study, the items related to the teenager's lifestyle (TQoL and AQoL) and Reactivity were the most problematic; however, the variance in response would suggest that it is useful to include these questions in the final version of the questionnaire. It may also be useful to assess each item to ascertain which distinguish best among asthma severity levels (e.g., using Rasch analysis and structural equation modeling, though a much larger sample size would be needed for such an analysis).

In conclusion, based on this initial validation of the CAQ-C (Singapore version), we recommend that the version to be further fine-tuned to improve the validity and reliability before being used widely in a clinical setting. The current form of CAC-C could serve as a suitable prototype where future HR-QoL instruments for asthmatic children could be built on, and focus groups could be conducted to further determine the relevance and importance of various items across different ages.

6.5 ACKNOWLEDGEMENT

We are grateful to Dr Davina French-the developer of CAQs for granting us the permission to adapt the questionnaires for use in Singapore and participating in the item selection. We would also like to thank the clinicians and staff of the specialist respiratory clinics for their assistance in patient recruitment. Last but not least, we are indebted to the patients and their family members who had selflessly taken time to participate in the validation process. They have not only provided valuable feedback about the questionnaires, but also opened up their hearts to share with us what it meant to have asthma-when you are just a kid!

Chapter 7. Conclusions

7.1 STUDY QUESTIONS AND MAJOR FINDINGS

In this final chapter of the thesis, the major findings made in this thesis are summarized and its potential contributions to asthma management highlighted. Suggestions for further studies will also be discussed.

The study started off with the general questions "What else needs to be done to improve the management of childhood asthma and improve patients' quality of life? What is the missing link?" We then broke down this broad question into more specific questions which are more manageable:

1. Is there a lack of parental understanding about childhood asthma which contributed to poor management? Will education be useful? If yes, who would need it most?
2. How do parents and asthma patients perceive asthma? How do they actually manage it at home? What are the things that influence their beliefs, attitudes and management?
3. What about the public? What do they think about asthma?
4. Could we adapt quality of life questionnaire to measure the health-related quality of life of children in Singapore? Will the adaptation be valid and effective?

From the results obtained as presented in the various chapters, our findings to those questions could be summarized as follows:

- There is a difference in parental understanding of asthma, even among patients who are cared in the same hospital. Overall, patients cared by specialist doctors had significantly better knowledge about asthma and its medication. Even though they are supposed to suffer from more severe asthma than patients managed in the general paediatric clinic, these patients had less school absenteeism caused by asthma exacerbation. Their parents' better understanding and knowledge of asthma could have contributed to the better asthma management and control. This indicates the importance of improving the knowledge and understanding of the disease among the caregivers towards better outcomes of the disease. Nevertheless, other than source of usual care, sociodemographic factors could also contribute to better management in patients cared by specialist doctors.
- Parents and patients have varying degrees of understanding about asthma. Our results show that the lesser they know, the more likely they will resist usage of long term preventers due to their fear of the side effects of steroids, and succumb to the temptation of finding quick and unproven "alternative cures". For most parents and patients in Singapore, there is a belief that food is central to the prevention, control and even treatment of asthma. From the discussions in the focus groups, sometimes, the parents' experience surrounding the diagnosis of asthma in their children could be traumatic, and primary health care providers

seemed to have provided insufficient information, and suboptimal pharmacological care.

- The public still have many myths about asthma, particularly concerning the use of long term inhaled steroids. Sometimes the fear of using long term inhaled steroids would border on paranoia as more would believe that "swallowing a life white mice" (about 25% of respondents) could cure asthma than disagreeing that "using long term inhaled steroid would cause addiction". Therefore, it is no surprise that parents are always tempted to stop the inhaled corticosteroids with the resultant poor control of asthma in their children.
- As an instrument in assessing health status among asthmatic children and adolescents, the CAQs are easy to use, and their formats are easily understood by young patients. Almost all respondents have no problems completing it. Interestingly, the results from the CAQ-B showed that parent and patient ratings of asthma severity correlated more closely than physician rated asthma severity.

The psychometric properties for most domains are within acceptable standards for the CAQ-B, but more varied in CAQ-C which is meant for older children. Items which are related to severity or distress in CAQ-C drifted from one domain to another across different countries. These problems could be contributed by social cultural differences among the countries, which affected the "relevance" and validity. For example, food is very important in Singapore, but not included in the CAQs. However, these observations may also be due to sampling problems as we have recruited patients who have well controlled asthma.

7.2 CONTRIBUTIONS

The contributions of the findings to address the research questions generally support the general theme that patient and public education efforts are important and could play an important role to improve the outcomes of patients. Generally, some recommendations that could counter some of the short comings in asthma management in particularly paediatric patients in Singapore would include the followings:

- Patients not under the care of specialists tend to come from lower socio-economic groups, have less knowledge about asthma, and have poorer control and outcomes compared to those cared by respiratory physicians. Hence, tailored, individualised education which addresses the patients' needs and beliefs could close the information gap between these two groups and improve the outcomes.
- Information needs about asthma are most crucial in the initial stages of asthma development or diagnosis and could avoid any difficulties faced by patients and parents. More education and counselling support need to be provided at the primary care levels, which is the first point of contact for many patients. This is an area that more efforts should be expensed.
- Patients and parents who do not know much about asthma are most susceptible to be influenced by incorrect information provided by people around them and develop compliance problems. Identifying and targeting these groups for specialized counselling would potentially yield significant outcomes.

- The public still have many misconceptions about asthma. This causes patients to have a lay referral framework that is not supportive of long term usage of preventers to control asthma, and sceptical about the use of inhaled corticosteroids. To counter these misconceptions, public education which addresses the specific concerns like inhaled steroids are important.
- Food plays a central role in the life of an asthmatic patient. It is attributed as a cause, trigger, and also a means to control and treat asthma. Food restrictions are an important means of management which could impact on the patient's quality of life. Healthcare professionals need to address the concerns about food seriously.
- The adaptation of extraneous quality of life instruments about asthma need to proceed cautiously in Asian societies where food is a major concern. As quality of life instruments specific to asthma focuses more on the social, environmental and exercise limitation concerns and do not address concerns about food, this could be a limitation it the relevance and reliability. Nevertheless, the use of a HR-QoL instrument in monitoring changes in health status in asthma patients should be encouraged to complement the monitoring of conventional biomarkers such as FEV1 etc.

7.3 LIMITATIONS

The limitation of each study in this thesis had been discussed in some details in each chapter. In summary, many of the limitations were related to sampling issues, and could have possibly been avoided, if there were sufficient resources to recruit a larger sample or participants with certain characteristics. Despite knowing the importance of conducting focus groups among target respondents to check the relevance and importance of each item, we also did not have the resources at the time of the adaptation of CAQs.

For example, because of the relatively small sample size, and the fact that patients were generally well managed, we were not able to draw conclusively whether the inability to differentiate between patients with severe asthma from the milder ones was and instrumental problem, or a sampling problem. The sample sizes in these studies were not large enough to perform exploratory factor analysis reliably and help to establish the items for each domain. Therefore, the sampling issues prevented us drawing conclusively whether it is feasible to adapt quality of life questionnaires for children with asthma which had been developed in western countries, even though the CAQ-B appears to be a valid and reliable instrument to be used in Singapore.

7.4 RECOMMENDATIONS FOR FURTHER RESEARCH

The studies and findings in dissertation have raised new concerns and research questions that need to be addressed in the future. These are:

- To what extent food restrictions which are strongly recommended play a role in controlling asthma? Are there scientific basis in these limitations?
- Qualitative studies to understand how asthma affects children and adult's quality of life. Questions which should be included include whether food limitations affect patients' quality of life, and how much it impacts.
- Studies on factors that affect the parents' perception of asthma severity, and how this in turn would influence their management strategies and the patients' quality of life. It will also be interesting to compare the influence of the management approach of parents vs. the patient with different levels of clinical asthma severity.
- Further studies on the structure of the Childhood Asthma Questionnaire, particularly with respect to the item drift observed in the CAQ-C.
- Studies on the cultural impact on HR-QoL in asthmatic patients by evaluating whether different activities have different meanings to people's quality of life in different cultures and countries.

We believe that the above studies will go complement the projects in this thesis, and serve to further elucidate observations and findings in the current thesis.

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