An investigation of the reasons parents and carers of children with asthma declined to attend self management education programs

Heather Smith
University of Wollongong

An Investigation of the Reasons Parents and Carers of Children with Asthma Declined to Attend Self Management Education Programs

A thesis submitted in partial fulfilment of the requirements for the award of the degree

MASTER OF NURSING

from

UNIVERSITY OF WOLLONGONG

by

HEATHER SMITH BN.

Grad Cert Asthma Education

DEPARTMENT OF NURSING

2006

CERTIFICATION

I, Heather Smith, declare that this thesis, submitted in partial fulfilment of the requirements for the award of Master of Nursing, in the Department of Nursing, University of Wollongong, is wholly my own work unless otherwise referenced or acknowledged. The document has not been submitted for qualifications at any other academic institution.

_____

Heather Smith

Date

TABLE OF CONTENTS

1 ACKNOWLEDGEMENTS 5
2 ABSTRACT 6
3 INTRODUCTION 8
3.1 Structure of the thesis 8
3.2 Asthma 9
3.2.1 Definition of asthma 10
3.3 Statement of the problem/issues 11
3.3.1 Asthma incidence/ prevalence 11
3.3.2 Mortality and Morbidity 11
3.3.3 The Health and Economic Burden of Asthma 12
3.3.4 Asthma Management 13
3.3.5 Health Behaviour 14
3.3.6 Self Management Education 15
3.4 Background to the Illawarra Asthma Service 15
3.5 Aim of the study 17
4 LITERATURE REVIEW 19
4.1 Asthma Management 20
4.2 Self Management 21
4.2.1 Self management in children- the role of the family 22
4.3 The National Asthma Council's Six Step Plan 24
4.4 Self Management Issues 27
4.4.1 Adherence 28
4.4.2 Adherence with monitoring 30
4.4.3 Medication Adherence 31
4.4.4 Adherence to trigger minimisation 33
4.4.5 Adherence to action plans 33
4.4.6 Adherence to regular medical review 34
4.4.7 Attendance at asthma self management education 35
5 THEORETICAL FRAMEWORK 38
5.1 Health Behaviour Models 38
5.2 The Theory of Planned Behaviour 40
5.2.1 Background - The Theory of Reasoned Action 40
5.2.2 Development of The Theory of Planned Behaviour 41
5.2.3 Behaviour 45
5.2.4 Behavioural Intention 46
5.2.5 Perceived Behavioural Control 46
5.2.6 Subjective Norms 47
5.2.7 Attitude 47
5.3 Relationship between constructs of the theory and asthma 51
5.3.1 Behaviour and Asthma 51
5.3.2 Behavioural Intention and Asthma 51
5.3.3 Perceived Behavioural Control and Asthma 51
5.3.4 Subjective Norms and Asthma 52
5.3.5 Attitudes and Asthma 53
6 METHODOLOGY 55
6.1 Research Design 55
6.2 Population and Sample 58
6.3 Data Collection 59

6.4 Data analysis....61
6.5 Ethical considerations....61
6.6 Validity and Reliability....63
7 FINDINGS....64
7.1 Overview of interviews....64
7.2 Application to the Constructs of the Theory of Planned Behaviour....77
7.2.1 Behaviour....77
7.2.2 Behavioural Intention....79
7.2.3 Perceived Behavioural Control....80
7.2.4 Subjective Norms....83
7.2.5 Attitude....87
7.3 Support....90
8 DISCUSSION....92
8.1 Themes....92
8.1.1 Self Confidence....93
8.1.2 Attitudes towards self management education....95
8.1.3 Experience of asthma....97
8.1.4 Support....99
8.1.5 Confidence in medical managers....101
8.1.6 Parental responsibility....102
8.1.7 Skills and Knowledge....103
8.1.8 Transport....104
8.1.9 Time....105
8.1.10 Intention....105
8.2 Limitations of the research....106
8.2.1 Recruitment....107
8.2.2 Methodology....108
8.3 Recommendations....110
8.4 Conclusion....110
9 REFERENCE LIST....112
10 APPENDICES....120
10.1 Appendix One: Information Sheet....120
10.2 Appendix Two: Consent Form....122

1 ACKNOWLEDGEMENTS

I would like to express my sincere thanks to the parents of children with asthma who took part in this study, and shared their experiences with me; my supervisors, Sandra Jones and Joanne Joyce, for their continued support, guidance, and advice; my colleagues within the Illawarra Asthma Service and Illawarra Health for their encouragement and support throughout the research; and my husband.

Heather Smith

2 ABSTRACT

The aim of this qualitative study was to investigate why parents or carers of children with asthma chose not to attend asthma self management education. Six semi-structured interviews were conducted with parents who had declined an invitation to attend the Illawarra Asthma Service.

Participants expressed that they felt confident in their ability to self manage their children with asthma, four of the respondents indicated that they already felt confident and did not feel they needed to participate in the education offered to them. One respondent sought self management education from an educator at her General Practitioners surgery; this family were able to implement many self management behaviours. The remaining respondent had previously attended the service and in their experience the benefits of attending were negligible and they believed they were doing everything possible to manage their children's asthma.

The Theory of Planned Behaviour was included as a theoretical framework to explain and predict this health behaviour. Major themes emergent from the interviews relating to the theory include self confidence, attitudes towards self management education, experience of asthma, skills and knowledge, transport, time, confidence in medical managers, and parental responsibility. Support, an additional theme, was identified which was not directly related to the determinants of behaviour change identified within the Theory of Planned Behaviour. This model of health behaviour has provided some insight into the issues related to attendance at self management education and adoption of self management behaviours for parents and carers of children with asthma.

Attitudes to self management education also had a strong relationship with this population's ability to adopt self management strategies.

A range of interventions have been proposed to identify those families that have not already implemented behaviours reflective of best practice in asthma self management and to facilitate attendance at self management education for these families.

3 INTRODUCTION

This research project was designed to explore the reasons for non attendance at asthma self management education. The study was conducted within a population of parents or carers of children with asthma referred to the Illawarra Asthma Service. Approximately two thirds of the families referred to this service choose not to attend; it is likely that there are a number of reasons contributing to this situation. This project has been undertaken in an attempt to identify these reasons and provide better understanding of the needs of the target population for future service development.

In the introductory chapter the reader is provided with an outline of the structure of the thesis, followed by background information about the area of asthma. Asthma is defined, and the problems and issues related to it identified including: asthma incidence and prevalence; mortality and morbidity; the health and economic burden; asthma management; health behaviour; and self management education. There is a brief history and explanation of the service provided to clients of the Illawarra Asthma Service as the study population was recruited from this service provider of asthma self management education. Finally the chapter provides a description of the aim of the study.

3.1 Structure of the thesis

This thesis initially provides an overview of asthma and identifies management issues in particular relating to self management education. The following chapter reviews the literature pertaining to best practice in asthma management and identifies the issues related to adherence with self management strategies. Behaviour change related to the

implementation of best practice in asthma management is considered within the theoretical framework, underpinned by the Theory of Planned Behaviour. The constructs of this theory are related to the issues associated with adopting self management strategies and are explored in detail. The remaining chapters include an outline of the methodology and findings of this research project. The findings are then presented within the context of the related behaviour change theory. This is a qualitative study which is exploratory in nature; there has been no attempt to provide a statistical analysis of the data. Discussion of the emergent themes, limitations of the research and conclusions are presented in the final chapter.

3.2 Asthma

Asthma is a widespread, chronic health problem and is largely a disease of modern civilisation. The prevalence and severity of asthma has increased significantly in the past 25 years; the burden to the community and the individual of mortality and morbidity is high (Woolcock, Bastiampillai, Marks & Keena, 2001; National Asthma Council, 2002; Bauman, Mitchell, Henry, Robertson, Abramson, Comino, Hensley & Leeder, 1992). Prevention of asthma is in its infancy and currently the goals of treatment include; relieving symptoms, preventing exacerbations, and maintaining best possible lung function (National Asthma Council, 2002; Rubinfeld, 2000). Best practice of asthma management in Australia incorporates The National Asthma Council's Six Step Plan; central to achieving best practice is the adoption of self management health behaviours such as monitoring asthma, recognising deterioration, and taking appropriate action - by the person with asthma or their carer (National Asthma Council, 2002; Sawyer, 2002).

3.2.1 Definition of asthma

There is a great deal of discussion and conjecture about what asthma is, with attempts to define it becoming increasingly complicated and obscure (Woolcock, 2000; National Asthma Council, 2002). The World Health Organization's definition will be used to inform this research project and it states:

"Asthma is a disease characterized by recurrent attacks of breathlessness and wheezing, which vary in severity and frequency from person to person. This condition is due to inflammation of the air passages in the lungs and affects the sensitivity of the nerve endings in the airways so they become easily irritated. In an attack, the lining of the passages swell causing the airways to narrow and reducing the flow of air in and out of the lungs."

(www.who.int/respiratory/asthma/definition)

Asthma is primarily a chronic inflammatory disorder of the airways, and is characterised by exacerbations of symptoms and periods of normal airway function between episodes (National Asthma Council, 2002). Those people with asthma who have frequent exacerbations will develop further airway remodelling and obstruction which may lead to irreversible disease in older adult life (Phelan, 2000). A chronic illness is by definition ongoing, cannot be cured and is associated with change through remissions and exacerbations of symptoms; neither the disease nor its consequences are static (Holman & Lorig, 2000). Asthma fits within this definition. Impacts tend to extend beyond physical effects, psychosocial adjustments and behaviour changes are required to live within the constraints of a chronic illness (Coppa & Boyle, 2003). It is proposed that the role of health services is to assist the person with asthma in facilitation, self care, enhancement of life and wellbeing through the promotion of

informed decision making and improving personal capacity (Weeks, McAvoy, Peterson, Furler, Walker, Swerissan & Belfrage, 2003).

3.3 Statement of the problem/issues

3.3.1 Asthma incidence/ prevalence

In the 2001 National Health Survey 11.6% of the population in Australia reported having asthma, approximately 2.2 million people. This translates to one in four young children, one in seven adolescents, and one in ten adults with asthma in Australia; these are some of the highest prevalence rates in the world, Canada, New Zealand and the United Kingdom also report similar prevalence rates. Asthma is more common among males than females in young children, while in older age groups this trend is reversed (Peat, 2000; Australian Institute of Health & Welfare, 2005).

3.3.2 Mortality and Morbidity

In the year 2003, 314 deaths in Australia were recorded as attributable to asthma, equating to three percent of all deaths that year. The death rate for asthma is low in children, less than 1:100,000 deaths and remains low until the age of fifty when the rate increases markedly, this is reported as probably complicated by the presence of chronic obstructive pulmonary disease and other co-morbidities (Australian Institute of Health & Welfare, 2005).

Impairment and disability caused by asthma is also significant, and symptoms can be limiting and restricting of daily activities. These limitations then impact on the individual's life in many ways, including social life, personal relationships,

employment and finances, all of which contribute to the burden of asthma (Gibson & Wilson, 2000; Goeman, Aroni, Stewart, Sawyer, Thien, Abramson & Douglas, 2002). Much of the morbidity and mortality related to asthma is potentially preventable through optimal medical management and adoption of self management strategies (Tettersell, 1993; Gibson, Coughlan, Wilson, Abramson, Bauman, Hensley & Walters, 2002; Bauman et al, 1992).

3.3.3 The Health and Economic Burden of Asthma

Population surveillance reveals that asthma is a significant burden on all aspects of health care; over 25% of children use asthma medications, over 15% often visit the doctor for asthma management, nearly seven percent have attended the emergency department, and over one percent have had an admission to hospital (Peat, 2000; Woolcock et al, 2001). Asthma is the most frequent cause of hospitalisation in the 0-14 age group, with an average length of stay of 2.3 days (Australian Institute of Health & Welfare, 2005).

In 2000-01 the Australian Institute of Health and Welfare estimated health care costs for asthma in Australia were $693, million, this was 1.4% of the total allocated recurrent health expenditure; pharmaceuticals made up more than half of these costs by way of reliever and preventer medication. Asthma is the sixth most common reason for General Practitioner consultations, with 153 medications prescribed per 100 consultations. The referral rate to specialist care is low, 2.7 per 100 consultations. Indirect costs of asthma have not been estimated but are considered significant; restrictions of activities of daily living such as attendance at school or work, self care and mobility issues have all been related to symptoms of asthma (Australian Institute of

Health & Welfare, 2005; Woolcock et al, 2001). In 1999 asthma was identified as a national health priority by the Australian Government because it is a common chronic condition with a substantial impact on the community and with clearly defined interventions that can reduce its impact on individuals and the community (Australian Institute of Health & Welfare, 2005).

3.3.4 Asthma Management

Considering the issues of asthma prevalence, mortality and morbidity, and the burden of asthma, the management goals identified include minimising the symptoms of asthma, maintenance of normal activities, minimal presentations to the emergency department or hospitalisations, and maintenance of normal lung function (National Asthma Council, 2002; Brown, 2001). The literature consistently refers to the achievement of these goals through optimal medical management and asthma self management (National Asthma Council, 2002; Gibson et al, 2002; Sawyer, 2002). For the person with asthma or their carer this is a process of self management whereby individuals make changes to asthma treatment in response to recognising deterioration in their asthma. The skills required include knowledge, problem solving, sense of control and the ability to make decisions and provide care (McCarthy, Hanson, Herbert, Wong, Brimacombe & Zelman, 2002). Research has indicated that adoptions of self management strategies are associated with reductions in health care costs and utilisation of health services (Foster, Kendall, Dickson, Chaboyer, Hunter & Gee, 2003; Bodenheimer, Lorig, Holman & Grumbach, 2002).

3.3.5 Health Behaviour

Optimal chronic illness management is highly dependent upon self management; the programs that facilitate self management are based in theoretical models of health behaviour and health education (Kolbe, 2002). Health behaviour models provide the theoretical framework to explain and predict health behaviours and self management attitudes which can then be used to develop programs and strategies to bring about behaviour change and improvements in the implementation of self management behaviours (Glanz, Lewis & Rimer, 2002).

The Theory of Planned Behaviour is a health behaviour model that provides a structure to identify the issues most important to a person's decision to perform a specific behaviour. This model considers the person's attitudes, subjective norms, perceived behavioural control, and intentions to perform the behaviour in question (Ajzen, 1991). The Theory of Planned Behaviour is relevant to this research project as the issues presented as determinants of attendance at self management education can be related to, and discussed under each of the constructs of this theory. This research project has aimed to explore the reasons for non-attendance at asthma self management education, through exploration of each of the constructs of this model. The Theory of Planned Behaviour has previously been used in contexts where intention to change behaviour has not been established or may be low, and may be used to target preventative health behaviours in community based samples. Constructs from this model have been demonstrated to be effective in alcohol and drug abuse, condom use, smoking behaviour and physical activity programs (Hardeman, Johnstone, Johnstone, Bonetti, Wareham & Kinmonth, 2002; Glanz et al, 2002).

3.3.6 Self Management Education

A key component of the National Asthma Campaign's Six Step Plan is the recommendation for education for the person with asthma and their carers (National Asthma Council, 2002). A Cochrane review of twenty five self management education programs found that participation in self management education reduced hospitalisations, reduced emergency department presentations, reduced unscheduled visits to the doctor, reduced days missed from work or school, and found improvements in reported nocturnal symptoms (Gibson et al, 2002). Self management education aims to provide the person with asthma and their carers with the skills and knowledge to identify and solve problems, and the confidence to manage asthma on a daily basis (Lorig, 2003). Effective self management encompasses engaging in activities that protect and promote health, monitoring and management of signs and symptoms of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes (Jayasuriya, Roach, Bailey & Shaw, 2001).

3.4 Background to the Illawarra Asthma Service

The Illawarra Asthma Partnership, which was convened by The Public Health Unit in 1990, brought together health, education and community key stake holders with an interest in asthma to investigate, plan and respond to asthma in the Illawarra region. This group comprised of the Public Health Unit, University of Wollongong representation from public health, education and nursing, Department of Education, Department of Respiratory Medicine, Illawarra Branch of the Asthma Foundation, NSW Ambulance Service, Division of General Practitioners, General Manager of Community Health, Child and Development Co-ordinator, Healthy Cities Illawarra,

multicultural health and physiotherapists, pharmacists, paediatricians, respiratory and emergency department specialists. This group developed a strategic plan for asthma services based on evidence and consensus. This strategic approach was implemented through a multi system approach as well as establishing an asthma education framework.

As a result of this planned approach in 1998, Illawarra Health's Community Health was successful in obtaining funding from the Department of Health to develop an education program for people with asthma. A program was developed which is evidence based and takes an innovative approach to community based management of asthma and adopts a primary health care framework.

The program adopts a holistic approach by incorporating clinical management, and strategies that target lifestyle factors, which may inhibit optimal asthma management. Education is individualised to each client and takes into account such things as the client's beliefs, abilities, culture and lifestyle. Behaviour change strategies incorporated into the programs interventions include goal setting, diary keeping and contracting of responsibilities (Jarvis, King, Simpson & Smith, 1998).

The program aims to target those people with moderate to severe asthma, the literature supports that these people are most likely to embrace change and to implement self management behaviours (Yoon, McKenzie, Miles & Bauman, 1991; Gibson & Wilson, 1996). Clients with asthma are currently recruited through hospital admissions and presentations to emergency departments in the Illawarra with asthma. General Practitioners are also invited to refer their clients with asthma. The service has evolved

into primarily a paediatric service, with adults attending the Department of Respiratory Medicine; this has facilitated maximum use of resources and improved uptake of the service. A recent evaluation of the Community Health service found participants of the programme had improvements in the impact of asthma on their lives with reductions in hospital admissions, emergency department presentations, and prednisone courses, and increases in visits to the doctor (Eagar & Hurst, 2003).

Currently approximately one third of the children referred to the service from the Illawarra Health emergency departments and the children's wards accept an invitation to attend. No information has been available on the reasons why the remaining two thirds of families do not proceed to undertake an asthma education program; it is likely that there are multiple reasons. Participation in self management programs has been reported elsewhere as a problematic and a complex issue with many reasons for non attendance proposed (Foster et al, 2003; Yoon et al, 1991; Sawyer, Zalan & Bond, 2002; Hull, Alexander, Morrison & McKinnon, 2002). Client needs and attitudes in relation to self management education have generally not been explored in the literature. Therefore, an important gap has been identified within the research base.

3.5 Aim of the study

This qualitative project aimed to investigate why parents or carers of children with a diagnosis of asthma choose not to attend self management education and to explore the experience of living with a child with asthma and the coping strategies employed by families. This was achieved by interviewing the parents or carers of children referred to the Illawarra Health's Community Health asthma self management education program who have declined an invitation to use the service. Their reasons for not participating in

the program will be explored, and emerging themes identified. Asthma services and educators within the Illawarra are currently unable to identify or meet the needs of the families who have declined an invitation to attend the service. Results from this research project may be useful to inform future practice and service delivery within the Illawarra region.

4 LITERATURE REVIEW

The literature review discusses the themes being explored in this project including asthma management, adherence, self management issues, behaviour change, and relationships between the child with asthma and their parent or carer. The National Asthma Councils (NAC) Six Step Plan is presented as the framework adopted in Australia to achieve best practice in asthma management. Compliance, concordance and adherence are defined and discussed. Adherence is then presented as a major theme as part of achieving best practice and through the application of the NAC 6 Step Plan, with the proposed outcome of improving quality of life for the person with asthma.

The literature search was conducted in Medline, Cinahl, Cochrane and Psycinfo; these are major databases in the fields of health and psychology. References relating to asthma were found mostly under health, health behaviour models are more predominant in the field of psychology. The following key words were used to search the databases, asthma, chronic illness, chronic disease, triggers, asthma management, self management, parents, relationships, education, clinics, attendance, non-attendance, compliance, adherence, health behaviour, and health models. Searches were limited to full text articles written in English between 1990 and 2005. The challenge was to refine and limit the searches using combinations of the key words, for example asthma and management, to provide articles relevant to the research, using the parameters outlined above a Medline search using the key words asthma and management provided 827 articles. Once a decision was made to use The Theory of Planned Behaviour it was further researched using the aforementioned data bases and a Google advanced search

of the internet. Citation indexes were used to follow up articles of particular relevance to the research project.

4.1 Asthma Management

Best management of asthma has been identified to incorporate optimal medical management and self management strategies; these should include self monitoring, avoiding triggers, maintaining the prescribed medication regime, recognising early signs of a deterioration in asthma and taking the appropriate action as detailed in the written asthma action plan (National Asthma Council, 2002; Rubinfeld, 2000; Sawyer, 2002). Much of the morbidity and mortality related to asthma is potentially avoidable; throughout the literature under-recognition and under-treatment are identified as contributing factors for both morbidity and mortality (Tettersell, 1993; Bauman et al, 1992; Kolbe, 2002). Underestimation of severity by the person with asthma could be as a result of a number of issues, including a lack of understanding of asthma and its treatment, non adherence, over reliance on bronchodilators, inadequate knowledge of signs of deterioration and failure to monitor their asthma (Tettersell, 1993; Bauman et al, 1992; Kolbe, 2002). Rejection by the client of a diagnosis of asthma further compounds the problems associated with management (Blessing-Moore, 1996; Ankney, Metzar, Meyerson & Shangle, 2001). These issues, if addressed, have the potential to reduce morbidity. An approach of co-management between the person with asthma and their medical manager which addresses health beliefs, attitudes and decision making capabilities is most likely to translate into behaviour changes which improve self management (Blessing-Moore, 1996; Ankney et al, 2001). The importance of the doctor-patient relationship has been identified as a priority of people with asthma

as significant for care and management of their asthma (Goeman, Hogan, Aroni, Abramson, Sawyer, Stewart, Sanci & Douglas, 2005).

4.2 Self Management

Self management of chronic disease is a relatively new paradigm as a means of providing care for a wide range of problems including asthma, diabetes, arthritis and stroke. The term self management makes reference to the activities people undertake to create order, discipline and control in their lives when incorporating the consequences of living with a chronic illness (Kralik, Koch, Price & Howard, 2004). The literature consistently reports that self management strategies are more likely to be adopted if they are in accordance with the individuals' health beliefs and personal experience of illness and if their concerns have been addressed (Aroni, Sawyer, Abramson, Stewart, Thien, Goeman & Douglas, 2003; Kralik et al, 2004; Trollvik & Severinsson, 2004).

A self management framework includes active partnerships with the health care team and daily management of the individual's own condition; self management education involves identifying the individual's needs and providing people with chronic disease with a sense of control, problem solving skills, confidence to deal with their problems and hence improving quality of life (Lorig, 2003; Bodenheimer et al, 2002). Effective self management encompasses engaging in activities that protect and promote health, monitoring and management of signs and symptoms of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes (Jayasuriya et al, 2001).

Three key elements identified as being successful in the promotion of self management by the health professional are effective communication, partnerships and a focus on

health promotion and healthy lifestyles. Communication provides insight into the person's thoughts, beliefs and expectations in relation to their asthma and willingness and confidence to manage. A partnership relationship allows for the development of common ground and trust within the relationship, goal setting and negotiation can then be utilised to develop strategies for short and long term gains (Bauman, Fardy & Harris, 2003). The emphasis is on the health professional to facilitate the communication and the person with asthma to be contributing to and driving the process to improve well being and strengthen self determination and participation in health care (Jayasuriya et al, 2001; Aroni et al, 2003). The client is the expert in their experience of living with asthma; the health professional is required to determine what knowledge the client needs and what behaviours must change to best manage their asthma and the skills and techniques to achieve these outcomes (Lorig, 2003; Bodenheimer et al, 2002). Parents may wholly or partially act as the proxy for self in the management of asthma in children; therefore it is relevant to briefly consider the parent and family relationship in relation to health.

4.2.1 Self management in children- the role of the family

Application of the concepts of self management in childhood asthma requires consideration of the principles of respect for individual children and families, importance of the family and participation in care and decision making (Franck & Callery, 2004). In this scenario self incorporates the child, the adult carers and the family. Parental beliefs strongly influence the ways in which they provide care for their children with asthma and these beliefs have a developmental progression which need to be incorporated into health services interventions (Kieckhefer & Ratcliffe, 2000; Dalheim Englund, Rydstrom & Norberg, 2001). In managing childhood asthma parents

are expected to monitor the child's illness and to implement the care prescribed. In addition to this they are also expected to provide emotional support and assume responsibility for the overall development of the child (Brazil & Krueger, 2002). Parents provide care for their children within the requirements of their legal responsibility and their perceptions of what is culturally and socially expected of them (Sidebotham, 2001). Parents or carers of children have a legal responsibility to provide the basic physical and emotional necessities of life, including providing necessary medical care (NSW Health, 2000).

Physical health and psychological well being has been demonstrated to be affected by the quality of family functioning and parent child relationships. Conflict within the family has been related to issues of adherence and the use of medical services (Johnson, Kent & Leather, 2005; Trollvik & Severinsson, 2004). Illness and hospitalisation disrupts family life and can be a stressful experience due to a number of factors including frightening and unfamiliar situations, pain or discomfort and separation from parents and siblings (Turner, 2005; Dalheim Englund et al, 2001). Attention to how families deal with illness can facilitate recovery through increased physical care, better use of coping strategies or lower stress levels, interventions which improve communication, family cohesiveness and expressiveness have been used to assist families living with chronic illness (Johnson et al, 2005; Trollvik & Severinsson, 2004). These strengths would be utilised in the adoption of self management behaviours within the family unit.

4.3 The National Asthma Council's Six Step Plan

It is now relevant to discuss asthma and self management within the framework of the National Asthma Council's Six Step Plan. This framework is then utilised by the researcher to inform the issues of self management. The National Asthma Council (2002) developed a comprehensive strategy to advise best practice in asthma management in the form of a six step plan. The components of the plan include:

1. Assess asthma severity
2. Achieve best lung function
3. Maintain best lung function- avoid trigger factors
4. Maintain best lung function with optimal medication
5. Develop a written asthma action plan
6. Educate and review regularly

The focus of discussion here is on self management and issues of adherence which have the potential to improve health outcomes for the person with asthma, only a brief outline of each of the six management steps is provided. Self management can be incorporated into all of these steps as demonstrated.

Step 1. Assess Asthma Severity

Assessment of asthma severity by the health professional is based on history, medication requirements and lung function (Rubinfeld, 2000). Descriptions of the nature of symptoms, their duration, and frequency, including time of day, sleep disturbance, severity, and the factors that trigger them are most useful (Jenkins, 2000).

Self management involves diary keeping and regular peak flow monitoring; this information provides an accurate history to base the assessment of severity. A comprehensive assessment of medication use should include both preventer and reliever medication. The frequency that reliever medication is used to relieve symptoms, the number of doses required to provide relief, and how long the reliever medication lasts are significant factors (National Asthma Council, 2002). These details can also be incorporated into diary keeping assisting in the assessment of asthma severity.

Step 2. Achieve Best Lung Function

The goal in achieving best lung function is to optimally manage the disease at the point of presentation. This includes treating the acute symptoms of obstruction and the underlying airway inflammation (National Asthma Council, 2002; Walters & Walters, 2000). The self management issues here include recognition of a deterioration of the asthma, adherence to the medication regime and correct use of the delivery device.

Step 3. Maintain Best Lung Function - Avoid Trigger Factors

Step three aims to maintain best lung function by identifying and avoiding trigger factors (National Asthma Council, 2002). Assessment of the role of allergy and identifying the allergens responsible for provoking the disease can be difficult. Clinical history is important and should include seasonal changes, symptoms associated with work, associations with other symptoms including eye and skin irritation, sneezing, allergic rhinitis and sinusitis (Thomson, 2001). Once again monitoring and diary keeping will be useful tools in helping to determine patterns and identify the triggers. Self management incorporates avoiding and minimising exposure to known triggers,

this may encompass a range of measures including reducing exposure to housedust mite through the use of mattress protectors, damp dusting, appropriate laundering of linen, minimising soft toys and furnishings; or using reliever medication and completing warm up exercises prior to exercise (Walls, 2000). A key strategy here is also the avoidance of environmental tobacco smoke; it may trigger an episode of asthma but also has a deleterious effect on airway reactivity which makes the airway more responsive to other allergens and triggers of asthma. Environmental tobacco smoke has been linked to increases in the incidence of asthma and increases in symptoms and the need for medication (McQuaid, Walders & Borrelli, 2003).

Step 4. Maintain Best Lung Function With Optimal Medication

Step four aims to maintain best lung function by optimising asthma control. Optimal control is achieved when the person is symptom free, not waking at night with asthma, not needing reliever medication more than three times per week, lung function is at personal best and side effects from medication are minimal (National Asthma Council, 2002). Monitoring asthma, avoiding triggers and maintaining medication regimes are the key self management strategies to achieve optimal control.

Step 5. Develop a Written Asthma Action Plan

The next step involves developing an individualised action plan with the aim to have an individual or their carer recognise deterioration in their asthma by monitoring peak flow or asthma symptoms and then responding appropriately. This requires both understanding of the individual's presentation of asthma and the action plan and the confidence to implement the plan. This is a key factor in reducing morbidity for adults and children through early detection of deterioration in asthma symptoms and taking

early remedial action. A written action plan is recommended to provide clear instruction for the person with asthma or their carer, which includes medication changes and when to seek medical advice (National Asthma Council, 2002; Milnes & Callery, 2003).

Step 6. Educate and Review Regularly

Asthma education is seen to be a core component of asthma management and can be incorporated into each step of the National Asthma Councils' Six Step Plan, it should be individualised to meet the needs of the client (National Asthma Council, 2002). Regular medical review is considered essential to evaluate the effectiveness of the previous interventions, to reinforce the strategies and to update the treatment regimen to match current severity (National Asthma Council, 2002). The major self management issue here is attendance at services which are able to provide education and medical review, and implementation of the recommended strategies by the individual with asthma or their carer.

This concludes the presentation of the best practice guidelines within the NAC's Six Step Plan, and it is relevant now to discuss the issues of self management in relation to these guidelines.

4.4 Self Management Issues

It has been previously stated that self management strategies are more likely to be adopted if they are in accordance with the individuals' health beliefs and personal experience of illness and if their concerns have been addressed (Aroni et al, 2003; Kralik et al, 2004), and much of the discussion revolves around issues of compliance

and adherence. Many authors eg. (Adams, Pill & Jones, 1997; Ankey et al, 2001; Tettersell, 1993; Chapmen, Walker, Cluley & Fabbri, 2000) use the terms interchangeably to refer to the extent to which an individual follows the health care regimen without making clear their understanding of the terms. Compliance has been defined elsewhere as obedience and following instructions, it has been associated with yielding, submissiveness and paternalism; and non compliance as deviant behaviour with the blame directed towards the individual with the illness (Sawyer & Aroni, 2003; Vermeire, Hearnshaw, Van Royen & Denekens, 2001; Donovan & Blake, 1992). These associations make the use of the word compliance unacceptable in the promotion of self management behaviours. The more appropriate term is adherence as it incorporates the broader concepts of concordance, co-operation and partnership, and is generally accepted within the literature to acknowledge the inclusion of the individual's choice and role in self management (Vermiere et al, 2001; Sawyer & Aroni, 2003; Brown 2001). Adherence is the most commonly used term and will be used within this thesis to mean concordance, co-operation and partnership.

4.4.1 Adherence

Adherence by the person with asthma or their carer affects many areas of management including monitoring of symptoms and peak flow, prevention therapy, avoidance of trigger factors, implementing the action plan and appointment keeping (Dinwiddie & Mulier, 2002; Kolbe, 2002). Different adherence behaviours are not necessarily strongly correlated, people may be adherent with one aspect of a regimen but not another; the non-adherent behaviour may be intentional - the individuals choice - or unintentional and can vary greatly over time (Fielding & Duff, 1999; Kolbe, 2002; Vermiere et al, 2001).

Non-adherence results in a significant financial burden to health care, it has been estimated that non-adherence with the doctor's advice on treatment is as high as 50%. This may be because up to 50% of information provided in a consultation is forgotten or misunderstood, and this may contribute greatly to the client's ability to adhere to recommended behaviours (Dinwiddie & Mulier, 2002). Attempts should be made to understand the influences on an individual's level of adherence and use these insights to modify the management strategies (Kolbe, 2002).

The significance of non-adherence with self management strategies for the person with asthma may include persistent symptoms that impact on quality of life for the client and their family and, for some, hospitalisation (Weinstein, 2000; Spector, 2000). However, the ability and desire of the person with chronic illness to be actively involved or adherent in self management has been shown to fluctuate with a number of factors, including length of time since diagnosis, disease severity, past and present life experiences, values and culture. In times of crises people with asthma have been found to choose giving responsibility to health professionals (Paterson, Russell & Thorne, 2001). Negative experiences such as a severe exacerbation of asthma, often result in a reassessment of views and behaviours and provide an opportunity to initiate change (Buston & Wood, 2000; Dinwiddie & Mulier, 2002).

Fundamental to achieving adherence is the development of a therapeutic relationship where the person with asthma or their carer feels involved in setting goals and making decisions. Treatments should be tailored to meet the individual's needs; some non-adherence may in fact reflect a rational decision in self management. Reflective listening, selective reinforcement and clarifying are communication techniques that can

be implemented to encourage self-efficacy and improve confidence and ability to self-manage (Aroni et al, 2003; Fielding & Duff, 1999; Lo, 1998). Social support and positive family relationships are also key factors (Kyngas & Rissanen, 2001; Malhi, 2001). Social persuasion has been identified as a means of enhancing confidence and outcomes in chronic disease management. This means enabling and empowering families to identify their needs, recognise their existing strengths, and to utilise social supports (Lorig, 2003; McCarthy et al, 2002). The asthma educator or health professional may provide family support on some levels through facilitating parents and carers to self manage by fostering mutual respect and trust, partnership relationships and engaging the family as an active participant in all aspects of care (McCarthy et al, 2002; Weeks et al, 2003).

4.4.2 Adherence with monitoring

Monitoring of asthma symptoms, or peak flow measurements, is recommended as a means of assessing asthma severity, and so providing some sense of control when the appropriate implementation of the action plan follows identification of deterioration (National Asthma Council, 2002; Putman, Burge, Tatemichi & Twohig, 2001). A drop of 20% in peak expiratory flow or an increase in variability denotes deterioration in the client's asthma – this can be a particularly useful measure for people with a poor perception of their own airway calibre (National Asthma Council, 2002; Putman et al, 2001). One study found that in the short term adherence with peak flow monitoring is quite good; however, long term adherence is poor, suggesting this monitoring should be limited to short periods of time (Cote, Cartier, Malo, Rouleau & Boulet, 1998). Spector (2000) reported as many as 22% of readings had been falsified or made up. Often peak flow monitoring was used by the individual to confirm the person's belief that

symptoms are severe. Osman (1996) found that people presenting to hospital with asthma did not use their peak flow regularly, in fact 30% had not used their peak flow meter in the month prior to their admission. Symptom monitoring should include accounts of night time symptoms, frequency and severity of wheeze and cough, incidence of exercise induced asthma, use and effectiveness of reliever medication (Jenkins, 2000).

Monitoring of peak flow and symptoms by way of diary keeping is important as a means of providing the medical manager with information on which decisions about optimal treatment regimes are based (Chapman et al, 2000). Tetersell's (1993) study found that 50% of respondents did not recognise the signs of deteriorating asthma, their monitoring skills were ineffective; and 32% failed to seek medical attention for severe symptoms.

4.4.3 Medication Adherence

Problems with adherence to a regimen of medication may incorporate only taking part of the prescribed medication, skipping doses or stopping the medication (Cochrane, Bala, Downs, Mauskopf & Ben-Joseph, 2000). One of the easiest ways, and often the only way, to determine this is to ask. However, people tend to overestimate their adherence, as do ratings from the doctor and estimates of the canister weight to determine the amount of medication used (Kolbe, 2002; Put, Van den Bergh, Demdts & Verleden, 2000). A concern is the person over reporting their adherence to please their doctor, even dumping doses to feign adherence, and are consequently prescribed unnecessary and sometimes harmful medication as a result of an apparent lack of efficacy (Weinstein, 2000; Chapman et al, 2000).

One of the main issues identified throughout the literature to affect a person's adherence to the medication regime is consideration of the person's beliefs; is the medication assigned importance, is it acceptable to them, effective, and even affordable (Goeman et al, 2002; Mansour, Lamphear & DeWitt, 2000; Put et al, 2000; Adams et al, 1997). Kieckhefer & Ratcliffe (2000) interviewed a group of seventeen parents of children aged 5-10 years with asthma; this study reported that 47% of parents of children with asthma were concerned about the long term effects of the medication. Experience of side effects, such as tremor, mouth and throat problems including voice changes, are all deterrents to adherence (Goeman et al, 2002). Many clients will weigh up the perceived risks and benefits of the prescribed medication (Goeman et al, 2002; Buston & Wood, 2000; Tetersell, 1993). Providing education which enables the client to make an informed choice and involving the client and their family or social support network in the development of the management plan is considered important to improve adherence (Spector, 2000).

Other practical considerations include establishing more simple and workable routines to minimise forgetfulness, and choosing devices that effectively deliver the medication to the lungs (Sawyer, 2002; Buston & Wood, 2000; Cochrane et al, 2000). The choice of an age appropriate device and the correct use is particularly important as inhaled medications are heavily relied upon for the treatment of asthma. This is particularly important when providing advice for children and their carers. Incorrect inhaler technique is a major contributing factor to poorly controlled asthma. This can be overcome by correct teaching at the time of diagnosis and with regular refresher sessions thereafter (National Asthma Council, 2002; Hall, 1996). A study that included

all devices found that 14% of patients develop a faulty technique over time (Hall, 1996).

4.4.4 Adherence to trigger minimisation

Avoidance of allergens is an integral management strategy for people with asthma, environmental modification to reduce exposure to known triggers can have a marked benefit for some individuals. However, the ease of modification needs to be considered, for example efforts to reduce housedust mite, including use of mattress protectors, laundering of linen and damp dusting have been shown to be effective only when stringently applied (Van Asperen & Mellis, 1994). Many people are unable to reduce their exposure to triggers such as housedust mite and mould due to financial constraints and availability of suitable affordable housing (Mansour et al, 2000). Exposure to cigarette smoke has been strongly linked to the development of asthma, and is considered by many to be the most harmful and avoidable pollutant and trigger. Various interventions have been designed, implemented, and evaluated to reduce children's exposure to environmental tobacco smoke and have ranged from attempting to modify parental smoking behaviour to counselling parents to quit smoking (Van Asperen & Mellis, 1994; McQuaid et al, 2003).

4.4.5 Adherence to action plans

This management strategy is recognised as instrumental in reducing morbidity related to asthma. The theory is for the person with asthma or their carer to make changes to treatment in response to recognition of deterioration in asthma severity; there should be clear guidelines for a therapeutic response in medication usage and an indication of when to seek medical attention (Fishwick, D'Souza & Beasley, 1997).

To promote adherence the plan should be developed in partnership taking into account the individual's experience of asthma and acknowledging the expert patient (Aroni et al, 2003; Milnes & Callery, 2003). The plan ideally incorporates problem solving skills, embraces self efficacy and should be individualised through the incorporation of the person's individual features or symptoms and perceptions of asthma (Bodenheimer et al, 2002; Milnes & Callery, 2003). Providing written action plans reinforces the information given at a consultation, Dinwiddie and Mulier (2002) report only 50% of a consultation is remembered.

4.4.6 Adherence to regular medical review

One of the biggest hurdles to overcome in achieving regular medical review is to legitimise asthma as a chronic health problem, in doing so making it acceptable to seek a consultation to review asthma management when the person is symptom free (Worstell, 2000; Goeman et al, 2005). The federal government's 3+ Asthma Plan for General Practitioners addresses this issue. However, in order to achieve regular medical review it must be seen as a valuable experience by the person with asthma and their carers - good communication skills which include interactive conversation, identifying client concerns, providing specific reassuring information and agreeing on goals are seen as integral to achieving this strategy (Sawyer, 2002; Fielding & Duff,1999).

Kolbe (2002) also advocates consistently seeing the same doctor over different doctors on different occasions, in this way a trusting relationship is fostered between the doctor

and the person with asthma. Opportunities for asking questions should be provided and understanding of instructions should be checked (Osman, 1996).

4.4.7 Attendance at asthma self management education

Education in asthma self management - which involves self- monitoring skills, regular medical review and a written action plan - has been shown to significantly improve health outcomes. There is a wealth of literature which promotes the use of education and the promotion of self management behaviours as a strategy to improve asthma management (Fishwick et al, 1997; Gibson et al, 2002; Lorig, 2003; Osman, 1996; Mc Carthy et al). However, it is generally accepted that knowledge alone will not achieve long term improvements (Tettersell, 1993; Osman, 1996), but education is a core component of the individualised approach to management (Gibson et al, 2002; Sawyer, 2002; Blessing Moore, 1996; Osman, 1996; Tettersell, 1993).

Attendance rates at asthma education programmes have been reported in the literature to range from 31-66%, resulting in lost opportunities to improve health outcomes for the client, and inefficient use of resources and facilities (Mason, 1992; Yoon et al, 1991). Many studies (Sawyer et al, 2002; Hull et al, 2002; Mason, 1992; Yoon et al, 1991) have considered the reasons for non-attendance; factors considered have included age, sex, age of diagnosis, education levels, and socio-economic factors. The study conducted by Sawyer et al (2002) reported "forgetting" as the major explanation for non-attendance, Twenty-seven percent felt the appointment was no longer necessary and 14% had other commitments; these explanations may be superficial and worthy of a deeper enquiry. Telephone reminders were trialled and found useful as a means of

improving attendance. Yoon et al (1991) approached people with asthma whom they thought should have been highly motivated to attend self management education - nearly seventy five percent of their target population had expressed an interest while in the hospital, but only 43% of this group then attended. This study considered sex, educational level, health insurance, and marital status, number of admissions, tobacco use and referral to specialist physician. Much of this evidence is inconclusive as no clear trends were identified; only one of the studies reviewed sought to identify clients' needs and attitudes to attendance. Lacey, Paulman, Reuter & Lovejoy, (2004) used semi structured interviews to explore participants' reasons for failing to attend scheduled appointments, issues identified included emotional barriers; perceived disrespect of the person's beliefs, opinions and feelings by the health professional; and a lack of understanding of the impact of missed appointments on the health system. Health beliefs and attitudes have been identified as much better indicators of health behaviour and attendance.

Attendance at a self management program is related to acceptance of the diagnosis, and belief that the condition is controllable. Those who believe there is an association between their lifestyle and health benefits are more likely to commit to behaviour changes (Foster et al, 2003; Cooper, Lloyd, Weinman & Jackson, 1999; Adams et al, 1997). Foster et al (2003) reported that people with significant morbidity as a result of chronic illness and few resources to support a healthy lifestyle were less likely to attend self management programs.

Self management education incorporates enhancing self-efficacy, or confidence to deal with a given situation and the client learning problem solving skills, useful at identifying problems from their own point of view and using action plans to find solutions. These skills are then applied to the medical, social, and emotional aspects of illness (Bodenheimer et al, 2002; Foster et al, 2003). Health behaviour models provide insight into explaining health behaviours, (Glanz et al, 2002), and in turn these can inform health practice and ensure that the design and implementation of health programs including self management education, maximise health gains.

5 THEORETICAL FRAMEWORK

In the previous chapters' discussion of asthma management it is clearly demonstrated that best practice is achieved through the adoption of self management practices and behaviours by the person with asthma or their carer. Health behaviour models provide some insight into explaining the adoption or rejection of health behaviours by individuals (Glanz et al, 2002). The theoretical framework for this research project explores the background of the models of health behaviours; the Theory of Planned Behaviour is presented in some detail with each of the constructs related to self management and best practice in asthma management.

5.1 Health Behaviour Models

Shinitzky and Kub (2001) report an increasing interest in behavioural determinants of health since the 1960's with acknowledgement of political, economic and social influences. There have been many theories developed, to explain health behaviours within individuals, groups and communities, and they provide a framework for practitioners to base interventions (Glanz et al, 2002).

Optimal chronic illness management is highly dependent upon self management; the programs which facilitate self management are based in theoretical models of health behaviour and health education (Kolbe, 2002). Health models provide insight into explaining health behaviours, and in turn these can inform health practice and ensure that the design and implementation of health programs maximise health gains. Several theories have a theme that behaviour change is a dynamic multiphase process that is highly individual (Glanz et al, 2002). Concepts referring to behavioural dispositions

such as social attitude and personality trait have played an important role in attempts to predict and explain human behaviour (Ajzen, 1991).

Common elements of the theories which are used to explain health behaviours in individuals include:

- a strong positive intention to perform the behaviour
- absence of environmental barriers
- skills
- the advantages of performing the behaviour outweigh the disadvantages of performing the behaviour
- social pressure or approval of the behaviour
- consistency between the behaviour and self image
- more positive than negative emotional reaction to the behaviour
- self efficacy or the confidence to perform the behaviour

(www.ohprs.ca/hp101/print/module4).

After extensive reading of the literature of health behaviour models available to health professionals, it was decided to apply the Theory of Planned Behaviour which is an extension of the Theory of Reasoned Action. Issues relative to the adoption of self management behaviours necessary to achieve best practice in asthma management can be discussed within the constructs of this model. It explains behaviour in terms that are changeable, for example beliefs and attitudes. Application of this model requires that the health professional considers the information needed to facilitate the development of a program capable of meeting an individual's health needs. It highlights the importance of understanding a person's beliefs about a health issue, whom the

individual sees as affecting their beliefs and behaviours, and what they perceive as the barriers to taking actions to promote their health (Ajzen & Fishbein, 1980).

5.2 The Theory of Planned Behaviour

5.2.1 Background - The Theory of Reasoned Action

The initial Theory of Reasoned Action was a precursor to the Theory of Planned Behaviour and was developed by Ajzen and Fishbein from a social psychology framework in 1967; it incorporates some of the central concepts in social and behavioural sciences and facilitates prediction and understanding of behaviour (Ajzen & Fishbein, 1980). This theory is based on the assumption that people are usually quite rational, and that they make systematic use of the information available to them, it also assumed that most social behaviour is under volitional control and can be predicted from intentions (Ajzen, 2002). There are four constructs to this model they are, attitude, subjective norms, behavioural intention and behaviour (Ajzen & Fishbein, 1980).

According to the Theory of Reasoned Action, the most important determinant of a person's behaviour is intent (Ajzen, 1985; Glanz et al, 2002). Intentions are a function of salient beliefs and information relative to the outcome. The strength of the intent to perform a particular behaviour is relative to the success of completing the behaviour. Intentions are assumed to capture the motivational factors that influence behaviour in situations where the behaviour is under volitional control, that is where the person can decide at will to perform or not perform the behaviour. The individual's intention to perform behaviour is a combination of attitude toward performing the behaviour and subjective norm. Attitude is an individual's positive or negative belief about the behaviour and the associated consequences, it is a subjective value. Subjective norms

are the individuals belief or perceptions of the approval or disapproval of significant others about the behaviour. Other considerations about performing the behaviour include evaluations of the outcome, and the motivation to comply with significant others (Ajzen, 1985; Glanz et al, 2002).

5.2.2 Development of The Theory of Planned Behaviour

In 1985 Ajzen added an additional construct concerned with perceived control over performance of the behaviour to the Theory of Reasoned Action; this expanded theory became known as the Theory of Planned Behaviour. This extension to the theory was made necessary by the original model's limitations and inadequacies in dealing with behaviours over which people have incomplete volitional control over their behaviours. The Theory of Planned Behaviour was designed to predict and understand motivational influences on behaviour not under the individual's volitional control, to identify how and where to target strategies for changing behaviour, and to explain behaviour in specific contexts (Ajzen, 1991; Glanz et al, 2002).

Everyday behaviours can be subject to unforeseen obstacles; the concept of perceived behavioural control was introduced to accommodate the non volitional elements potentially inherent in all behaviours (Ajzen, 2002). Behaviour change is more easily predicted when the individual's perception of degree of control is considered, especially when there is a high correlation with actual control. Actual control is represented by such factors as availability of requisite opportunities and resources, for example time, money or skills (Ajzen, 1991; Glanz et al, 2002).

Thus according to the Theory of Planned Behaviour human behaviour is guided by three kinds of considerations, behavioural, normative and control beliefs. Behavioural beliefs are about the likely consequences or other attributes of the behaviour, normative beliefs relate to beliefs about the normative expectations of other people, and control beliefs about the presence of factors that may further or hinder performance of the behaviour. Behavioural beliefs then produce a favourable or unfavourable attitude towards the behaviour, normative beliefs result in perceived social pressure or subjective norm; and control beliefs culminate in perceived behavioural control, the perceived ease or difficulty in performing the behaviour. Behavioural intention is formed as a result of attitudes towards the behaviour, subjective norms, and perceived behavioural control. Finally with sufficient actual control over the behaviour, people are expected to carry out their intentions. Many behaviours are limited by volitional control, therefore perceived behavioural control is considered in addition to intentions (Ajzen, 2002).

Attitude toward the behaviour, subjective norms with respect to the behaviour and perceived control over the behaviour have been found to predict behavioural intentions with a high degree of accuracy (Hardeman et al, 2002; Glanz et al, 2002). Behavioural intentions, in combination with perceived behavioural control can account for considerable proportion of variance in behaviour (Ajzen, 1985). The theory assumes that the relative importance of each of these factors varies with the intention under consideration, or with the individuals involved (Ajzen, 1985). The theory does not address the origins of people's beliefs which may be influenced by age, gender, ethnicity, socioeconomic status, religious affiliation, mood, personality, and past experiences amongst many others as the theory postulates that it is the beliefs that

influence behaviour not their origins (Ajzen & Fishbein, 2005). A visual representation of the Theory of Planned Behaviour and the constructs from this theory in relation to self management of asthma is presented on the following pages.

The Theory of Planned Behaviour has been used in contexts where intention to change behaviour has not been established or may be low, and may be used to target preventative health behaviours in community based samples. This model of behaviour change has been demonstrated to be effective in a wide range of behaviours with review papers citing alcohol and drug use, condom use, smoking behaviour, physical activity programs (Hardeman et al, 2002; Glanz et al, 2002) and food choices (Hardeman et al, 2002). The Theory of Planned Behaviour model provides methods for identifying those issues that are most important to a person's decision about performing a specific behaviour, there are potentially ideal opportunities for developing self management behaviours in relation to asthma management.

THE THEORY OF REASONED ACTION AND

THE THEORY OF PLANNED BEHAVIOUR

The shaded section represents the Theory of Reasoned Action; the entire diagram represents the Theory of Planned Behaviour (Glanz et al, 2002).

5.2.3 Behaviour

The theory incorporates central concepts of the social and behavioural sciences, and defines them in such a way as to permit the prediction and understanding of particular behaviours within specified contexts. Behaviour is defined as a specific single act or a set of actions and should not be confused with outcomes (Ajzen & Fishbein, 1980). Intention - which has been influenced by attitude, subjective norms with respect to the behaviour, and perceived control over the behaviour - is the key predictor of behaviour (Ajzen, 1985; Ajzen, 1991). According to the Theory of Planned Behaviour, social behaviour follows more or less well developed plans. The success of an attempt to execute the behavioural plan depends not only on the effort invested, but also on the person's control over other factors, such as information, skills and abilities, willpower, time, and opportunity (Ajzen, 1985). Intention, perception of behavioural control, attitude toward the behaviour, and subjective norm each reveals a different aspect of the behaviour, and each can be used as a point of intervention in an attempt to change behaviour (Ajzen, 1991). Behaviour change methods used to alter components of this theory include information, persuasion, increasing skills, goal setting, rehearsing skills, modelling, planning and implementation, and social encouragement and support (Hardeman et al, 2002). The desired behaviour for this population group is adherence to self management strategies that incorporate each of the National Asthma Council's Six Step Plan.

5.2.4 Behavioural Intention

This construct is the product of attitudes, subjective norms, and perceived control, and is central to the Theory of Planned Behaviour. Behavioural intention is assumed to capture the motivational factors that influence a given behaviour and is indicated by the person's subjective perception and the probability that the behaviour will be performed (Ajzen, 1991). The stronger the individual's intention to perform the behaviour in question the greater the likelihood of success. Unforeseen events may impact on the intention to behave, the greater the time lapse between intention and behaviour the greater the chance of intention changing (Ajzen, 1985; Ajzen, 1991). Intention is the immediate determinant of behaviour, and when an appropriate measure of intention is obtained it will provide the most accurate prediction of behaviour (Ajzen & Fishbein, 1980).

5.2.5 Perceived Behavioural Control

The overarching concept of perceived behavioural control is comprised of two components: self efficacy or perceived power, which deals largely with the perceived ease or difficulty of performing the behaviour, and controllability, the extent to which the behaviour is controlled by the performer (Ajzen, 2002). The construct refers to the perceived ease or difficulty of performing the behaviour of interest, it is assumed to reflect past experience as well as anticipated impediments and obstacles. People's behaviour is strongly influenced by their confidence in their ability to perform. These beliefs may in part be based on second hand information about the behaviour, by the experiences of acquaintances and friends, and may influence choice of activity, preparation, the effort expended and the emotional reactions to the chosen activity. Perceived control is a subjective measure and is determined by the beliefs related to the

presence or absence of facilitating factors or barriers, and their power to overcome any obstacles to the intended behaviour and not to a generalised predisposition (Ajzen, 1991; Glanz et al, 2002; McKenzie & Smeltzer, 2001). Facilitators and barriers for the individual may include skills, and personal and community based resources. A high level of perceived control should strengthen a person's intention to perform the behaviour, and increase effort and perseverance, thereby indirectly affecting behaviour (Ajzen, 2002).

5.2.6 Subjective Norms

Subjective norms are assumed to be functions of beliefs and are referred to as normative beliefs, and a motivation to comply. Normative beliefs are concerned with the input from significant others, that is perceived social pressure; approval will result in a positive subjective norm. Normative beliefs will be further reinforced where the person is motivated to meet the expectations of significant others, that is when the individual cares about what others think, and there exists a motivation to comply (Ajzen, 1985; Ajzen 1991; McKenzie & Smeltzer, 2001). To obtain a complete measure of subjective norm it is proposed that two types of norm are required. Firstly, injunctive, that is perceptions of what others think one should do and secondly, descriptive, perceptions of what others are doing (Ajzen & Fishbein, 2005).

5.2.7 Attitude

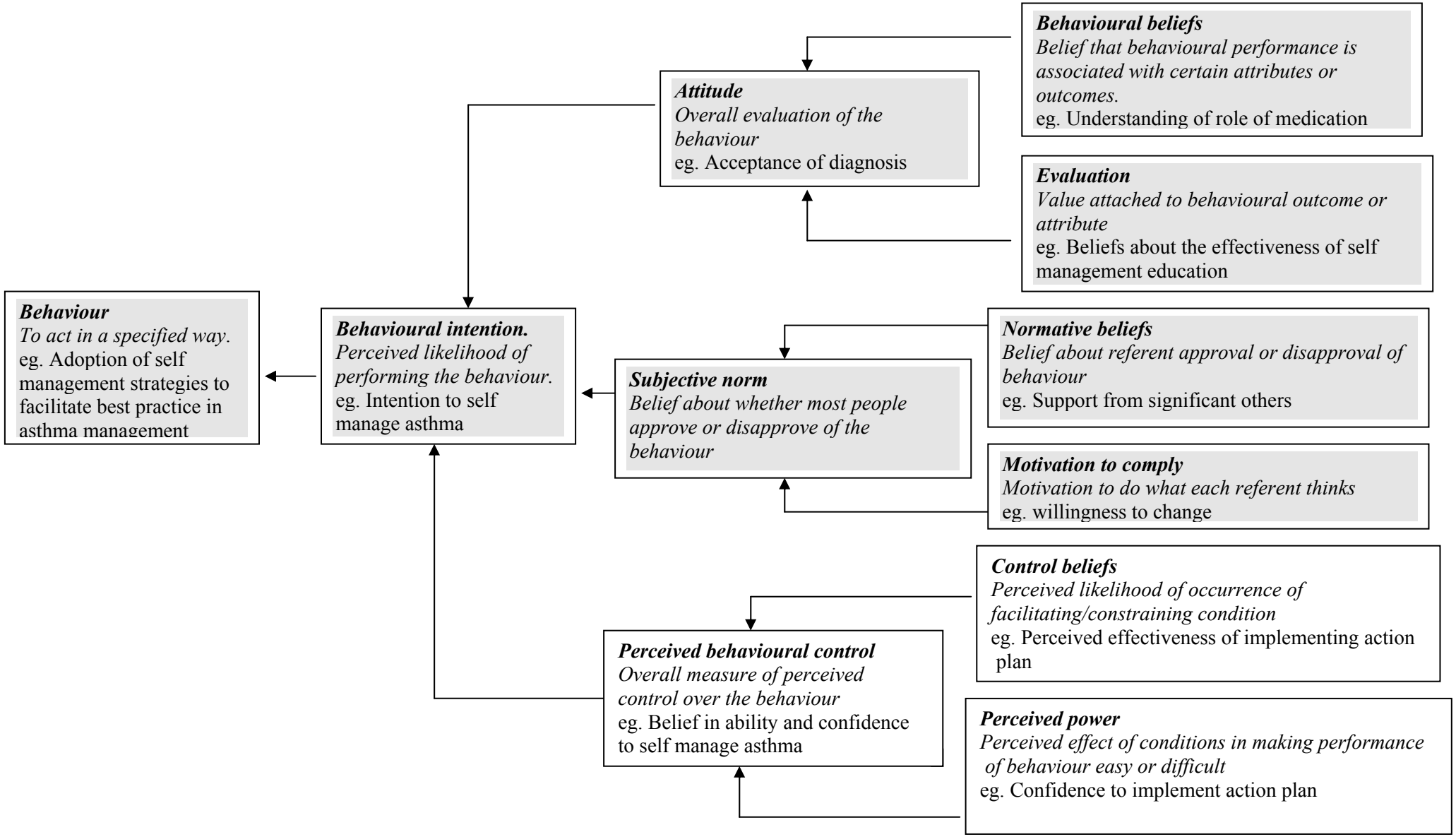
Ajzen (1985) defines attitude as the individual's salient beliefs about outcomes or attributes of performing the behaviour, which is then weighted against the evaluations of those outcomes and the value attached to them. Attributes that are linked to the behaviour are already valued positively or negatively from previous experiences or

exposure, we automatically and simultaneously acquire an attitude toward the behaviour (Ajzen, 1991). Attitude is an overall evaluation of the behaviour and is determined by salient beliefs about that behaviour. Each salient belief links the behaviour with some valued outcome or attribute. Attitudes are created over time and are reflections of individual and group experiences within a cultural setting (Ajzen, 1985; Ajzen, 1991).

Behavioural beliefs are determinants of attitude, a person who perceives an advantage of performing the behaviour outweighing the perceived disadvantages of performing the same behaviour is likely to form a positive attitude towards that behaviour (Ajzen, 1991). It is generally recognised that people can concurrently hold two attitudes toward a given behaviour; one implicit and often unrecognised and the other explicit and under conscious control. The implicit attitude is assumed to be automatically activated, where the explicit attitude requires cognitive effort (Ajzen & Fishbein, 2005). An attitude toward a given behaviour is only meaningful where they are compatible with the behavioural criterion in terms of target, action, context and time elements, so must be defined at the same level of generality or specificity. General attitudes have been found to be poor predictors of single behaviours, however, they correlate strongly with behavioural aggregates, and single behaviours were well predicted from attitudes toward the behaviour (Ajzen & Fishbein, 2005).

TABLE OF CONSTRUCTS AND DEFINITIONS OF THE THEORY OF PLANNED BEHAVIOUR

WITH IMPLICATIONS FOR ASTHMA SELF MANAGEMENT



5.3 Relationship between constructs of the theory and asthma

5.3.1 Behaviour and Asthma

The desired behaviour for a person with asthma is to adequately self manage their symptoms of asthma within the best practice guidelines recommended by the National Asthma Council's Six Step Plan.

5.3.2 Behavioural Intention and Asthma

The intention of a person with asthma to adhere to self management strategies may be strong at the time of an exacerbation, but as time passes with good control adherence becomes less important. The literature consistently reports that people with a recent severe episode are more likely to be motivated for behaviour change and are also at risk for future severe exacerbation of their asthma (Yoon et al, 1991; Blessing-Moore, 1996).

5.3.3 Perceived Behavioural Control and Asthma

Perceived behavioural control for the person with asthma may include information, access to services, and the ability to monitor and assess severity of asthma and the confidence and skills required to implement their action plan (Huang, 1997). Self-control and autonomy is reported to be important for people with chronic illness and one way for individuals to achieve this is by self-regulation of the prescribed medication and management plan (Tettersell, 1993). Self efficacy is expected to improve each time the person with asthma is successful in managing an exacerbation of symptoms, this then has a flow on effect to improve actual controllability.

5.3.4 Subjective Norms and Asthma

Clients often make their judgements on a social basis and are influenced by family, peers and previous experiences (Tetersell, 1993). Support from health professionals, medical managers, family and friends have been found to be statistically significant in predicting adherence with health regimens (Kyngas & Rissanen, 2001; Chapman et al, 2000; Fielding & Duff, 1999). Support may include encouragement, rapport building, positive feedback and emotional support. A key finding in the literature is that major support persons should be identified and included in the planning of care to achieve adherence in self management strategies (Kyngas & Rissanen, 2001; Trollvik & Severinsson, 2004; Fielding & Duff, 1999).

Optimal medical management and self management strategies are consistently reported in the literature as being key factors in managing chronic health issues (Aroni et al, 2003; Bodenheimer et al, 2002; Lorig, 2003). One of the key strategies recommended to achieve this goal is through the use of effective communication skills by the health professional, it is hoped this will foster partnership relationships between the person with asthma and their carer, and the medical manager (Shinitzky & Kub, 2001; Fielding & Duff, 1999); in this way the medical manager may be able to provide a supportive role and become a person of significance to the child with asthma and their family. The importance of the doctor patient relationship has been identified as significant by people with asthma in the achievement of asthma management (Goeman et al, 2005).

5.3.5 Attitudes and Asthma

The overarching attitude of the person with asthma is seen to have a modifying effect on the significance of the diagnosis for the individual. Adams et al (1997) identified strong links between the meanings given to asthma and the strategies of normalisation, self-identity and disclosure. Negative connotations and feelings of stigmatism may contribute to the disruption of daily life (Adams et al, 1997). A person's own health beliefs are important, and in order to take appropriate action a person must believe that there is a threat to their personal health and that the recommended action will reduce or remove this threat. Underpinning this belief is the perception of susceptibility to the disease and the potential severity of the impact on their wellbeing (Vermeire et al, 2001).

Attitudes to asthma may have a considerable impact on the individual or their carer's ability to recognise deterioration in asthma and to take appropriate action. A person who does not believe that asthma will threaten their personal wellbeing is not likely to seek a written action plan, monitor their symptoms or peak flow or take medication that has no immediate effect. The time and energy required to complete the regime may not be seen as worthwhile by the person with asthma, and medication may be seen as ineffective or the side effects too troublesome and monitoring unnecessary (Toelle & Ram, 2002; Ankney et al, 2001). In these ways attitudes can be seen to impact greatly on each of the self management strategies. Adoption of self management strategies has been identified as an effective means of reducing the burden of asthma and issues of morbidity which have been raised previously.

The role of health services in general, and the asthma educator in particular, is to try and reshape negative attitudes, beliefs and perceptions to empower the person with asthma or their carer to adopt self management behaviours in line with best practice. This can be achieved through the use of sensitive motivational interviewing techniques (Stott, Rees, Rollnick, Pill & Hackett, 1996; Schinitzky & Kub 2001). Motivational interviewing incorporates respect for autonomy, empathy, and reflective listening skills in a safe environment where clients feel able to reveal personal information. Healthcare professionals have a responsibility to take into account the individual's experience of illness and to adopt an empathetic understanding of the impact illness has on their lives and the lives of their families to foster successful communication (Trollvik & Severinsson, 2004). Adoption of this technique may help to change the attitudes of the client towards more positive approaches to, and implementation of, self management behaviour. Each session should address the needs, concerns, opinions and emotions of the client (Shinitzky & Kub, 2001).

This concludes the presentation of the health behaviour model, The Theory of Planned Behaviour and its application to best practice in asthma management. This model of health behaviour has provided some insight into the issues related to the adoption of self management behaviours for people with asthma and their carers. Of interest to this research project is non attendance at self management education, this phenomena was explored through the use of semi structured interviews as outlined in the following chapter.

6 METHODOLOGY

This chapter provides an overview of the research methods and support for the use of these methods. A description of the sample population is included as well as the recruiting process, process of data collection and analysis. The ethical considerations relevant to this project are also presented, with a discussion of the validity and reliability of the research methods.

6.1 Research Design

The researcher sought to fully explore the participants' reasons for non attendance at self management education and to understand the experiences and feelings of the parents or carers of children with asthma. Participants had been referred to the Illawarra Asthma Service for self- management education following a presentation to hospitals within the Illawarra and Shoalhaven. It was identified that the aim of the project could best be achieved through qualitative field research because it allowed for an exploration of the beliefs and attitudes of the study population. Qualitative field research was identified as the relevant discipline of enquiry for examining the personal meanings of individuals' experiences and actions in the context of their social environments (Polger & Thomas, 1991). Qualitative approaches to research originate in social anthropology and sociology and are used where the researcher is trying to understand a phenomenon from the perspective of the participants, aiming to be objective and to consider all options. In depth interviews are frequently used, and generally provide rich data from a relatively small number of participants (Crookes & Davies, 1998). This approach has been used widely in

research relevant to midwifery, nursing and health care (Crookes & Davies, 1998). Qualitative field research relates to this project because the researcher aimed to objectively explore all reasons for non attendance at self management education from the viewpoint of the parents or carer's of children with asthma. It is an exploratory study and no attempt has been made to complete a statistical analysis of the data.

The researcher adopted a phenomenological approach as the key focus was directed towards the participants' subjective perceptions of their own experiences. Phenomenology is the investigation and direct study of personal experience and the understanding of the nature of human consciousness (Polger & Thomas, 1991). Meaning is sought through the communication of the experience to the researcher with an appreciation and emphasis on the complexity of human experience (Crookes & Davies, 1998). Literally, phenomenology is the study of "phenomena": appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience (www.phenomenologycentre.org/phenom.htm).

This project used semi-structured interviews; the aim of the researcher was to gain an understanding of each of the participants' experience of living with a child with a diagnosis of asthma, to explore their beliefs about the service that had been offered to them and their reasons for not attending. In a semi-structured interview the questions are specified but the interviewer is free to probe beyond the answers in a manner which may allow further elaboration of the response (May, 2002). This may reduce the comparability of the interviews within the study but provides a more valid description of the participants'

values, attitudes and behaviours and involves an in-depth exploration of the topic of interest (Minichiello, Aroni, Timewell & Alexander, 1996).

Surveys were not considered as the researcher believed this method of data collection would not facilitate a full understanding of the process by which the parents and carers adopt particular values or behaviours relative to optimal asthma management. There was also concern that the participants may interpret the questions in a manner that was not intended, and that there was no opportunity for clarification or shared understanding in the use of surveys (May, 2002).

Another possible method was focus groups as a form of group interview that have been used successfully in assessing and understanding health behaviours. The group process is seen as an effective way of exploring and clarifying views, they allow participants to react to and build upon the responses of other group members (Crookes & Davies, 1998). The researcher did not opt for this method of data collection as the research question was considered quite personal and not without social constraint. It was anticipated that responses would be quite individual and it may not have been possible to fully explore each participants experience within a group situation. In a group setting responses of the participants are not entirely independent, secondly discussion may be directed by dominant participants and this may be inhibiting for other participants (Minichiello et al, 1996).

6.2 Population and Sample

The goal was to obtain a study sample that was representative of the population of interest, that is, parents or carers of children with asthma that chose not to attend self management education and to avoid biases in selection. This study population was recruited from referrals to the Illawarra Asthma Service between March 2003 and March 2004. Illawarra Area Health's, Community Health initially approached by letter those parents or carers of children who had been referred to the Illawarra Asthma Service and who had declined to attend, eighty six letters were sent in a staggered mail out over six months; this included all families in this population of interest entered on the Illawarra Asthma Service database within the previous twelve months and excluded the researchers client group. Eight families responded and were subsequently contacted by the researcher. One family was excluded from the research due to a conflict of interest with the researcher, also rostered as service provider to this family; a further family became too busy with other issues to participate.

Beyea and Nicoll (1997) identify an inherent risk of sampling bias because the population of interest may not be represented accurately thus limiting the generalisability of the findings beyond the study sample. In this study there is high risk of sample bias as the researcher is seeking a commitment to participate in the study from a population that has not attended self management education; some may have declined the initial invitation, others have made an appointment and failed to attend.

Six interviews were conducted by the researcher, providing a range of responses for interpretation and adequate data for analysis. Increasing the sample size would not have changed the sample bias as the recruitment process would need to remain the same and the bias is inherent in the population of interest (Polgar & Thomas, 1991).

6.3 Data Collection

Six families were interviewed by the researcher; between June and November 2004. Formal interview times ranged from fifteen to forty minutes, however, the researcher spent between sixty and ninety minutes with each participant. Time outside the formal interview was spent explaining the research, achieving informed consent and becoming familiar with the participants. All interviews took place within the participants' family home, at a time and location requested by the participants. Other venue options included The University of Wollongong or a neutral venue, their reasons for choosing their family home were not explored. It is considered preferable to conduct this type of research within the natural environment (Polger & Thomas, 1991), in this project the participants chose for the interviews to take place in their homes. This was considered acceptable to the researcher who has extensive experience working with people within their homes; therefore the researcher was comfortable in this environment and felt competent to address any issues that may have arisen. The research focused on understanding of the families' experience of asthma and the choices made in attending self management education by the individuals participating, the researcher aimed to develop some rapport with the participants throughout the interview to facilitate communication and to achieve the objective of the research.

The interview questions generally included:

- Would you tell me about your experience of your child's asthma?
- How do you feel about your child's asthma?
- How has it impacted on your lives?
- Did you feel you had adequate support at this time?
- Is there anything you try to do to help manage the asthma?
- How does that make you feel?
- What were your thoughts, feelings, expectations when the asthma educator contacted you?
- What were your reasons for declining the offer?

Interviews between the researcher and participants were audio recorded and later transcribed verbatim by the researcher. All participants were agreeable to this process, however on some levels this was found to be inhibiting for both parties as evidenced by the resumption of dialogue after the tape had been stopped. Conversations after the tape had been turned off were sometimes more forthcoming and attempts were made to capture this data. This method of recording data does ensure that the record of interview is accurate and meanings and interpretations can be validated (May, 2002). The researcher also made field notes following each interview to supplement the data, these notes were added to the verbatim transcripts.

This process has achieved the goals of the researcher by providing a rich source of data relevant to the project. Data has been collected in a manner which allows for provision of

accurate records of the interviews for later analysis and has complied with the conditions of the University of Wollongong Human Research Ethics Committee approval.

6.4 Data analysis

A thematic data analysis of the interviews used QSR NUD*IST Vivo (NVivo), a software program that enhances accuracy, thoroughness and rigour in qualitative data analysis (Richards, 1999). The transcripts were coded according to subject matter within the data as seen by the researcher and in line with the issues identified within the literature, for example, self management strategy, crisis management, skills, confidence. Subject matter was then grouped into broad categories such as asthma experience, people and strategies. The software package allows the researcher to code the transcripts and provides a database to store ideas and to sort the information. Relationships between the data sets can be viewed within the software program; this enhances the researcher's ability to identify common themes and threads within the data. The search tool is utilised to ask questions and to develop and test theories, by providing easy access to the relevant sections of text.

6.5 Ethical considerations

Initially approval was sought and gained from the University of Wollongong Human Research Ethics Committee; with Reference Number: ES HEO 3/376 dated April 5th 2004. Permission to undertake the research according to the requirements of the ethics approval from the University of Wollongong Human Research Ethics Committee was granted by the Director of Community Health Services and the Chief Executive Officer, Illawarra Health.

At the point of initial contact Illawarra Health provided their eligible clients with an explanation of the research and an invitation to participate. Upon commencement of each interview the participants were provided with a verbal explanation of the study and an information sheet which outlined the purpose of the research, contact details of the researchers responsible and provided written documentation of their rights as participants in the research (see Appendix One), the participants were then asked to sign a consent form (see Appendix Two). The consent form clearly stated that participation was voluntary, and withdrawal of consent was an option at any time through the research. Consent was informed through the information sheet and the verbal explanation of the researcher. Before the interview commenced, participants were reminded that they can withdraw their consent at any time.

Clients of the Illawarra Asthma Service were assured that their decision to participate or not participate would have no bearing on any future relationship with Illawarra Health and the Illawarra Asthma Service. To ensure clients were protected from real or perceived feelings of disadvantage, clients who would normally be seen by the researcher in the role of community asthma educator were excluded from the study.

All efforts were made to ensure that interviews were conducted in a respectful and non-judgemental manner. Confidentiality has been maintained at all times, participant's details and transcripts are locked in a filing cabinet at the University of Wollongong. All data has been de-identified and coded prior to analysis and presentation.

6.6 Validity and Reliability

Crookes and Davies (1998) identify credibility, dependability, transferability and confirmability as the constructs of rigour in qualitative research. Credibility or validity is achieved through accurate descriptions of the research setting and research participants (Crookes & Davies, 1998). Participants have been recruited from referrals to the Illawarra Asthma Service, an explanation of this service and the recruitment process has been detailed previously. Dependability and reliability in this study was sought through systematic data collection and interpretation; this also facilitates reliability of the analysis. This research has limited transferability, Illawarra Health achieved a nine percent response rate from the invitations sent out, and results cannot be assumed to be relevant to those who did not respond. The researcher acknowledges some unavoidable influence in the interview process, however, direct quotes are provided in the following chapter, findings, to provide the reader with some insight into the data collected. This process facilitates confirmability (Crookes & Davies, 1998). Crookes and Davies (1998) define confirmability as objectivity, and recommend that researchers fault their own methodologies and strive for completeness to achieve it. Rigour is also achieved through the sharing of ideas, and discussion and feed back from the research supervisors. These sessions are also useful to minimise the bias and subjectivity of the researcher.

7 FINDINGS

In this chapter a description of each of the interviews is provided and the findings of the research project are presented. Major themes that have emerged from the data are then considered under the constructs of the theoretical framework of the project, the Theory of Planned Behaviour. Findings, including a recurrent theme that resulted from the analysis of the data that could not be discussed adequately within the constructs of the Theory of Planned Behaviour, are also presented in this chapter.

7.1 Overview of interviews

Six interviews were conducted between June and November 2004; each was conducted in the participant's home and was audio taped for the purpose of analysis. Time was spent with each participant prior to the commencement of taping, the aim of the researcher was to familiarise the participants with the research process and to create an environment which would be conducive to sharing personal and detailed accounts of their experiences of asthma and attendance at self management education. The times given for each interview only include the formal interviewing time. The purpose of the research was explained and consent forms signed by the participants. Participants were informed verbally and in writing of their ability to withdraw consent at any time.

A brief synopsis of each participant's experience of their child's asthma and coping strategies is presented for each interview. All names have been changed to protect the identity of participants and their children.

Interview One

Date: 28th June 2004 Time: 1600

Interviewer: Heather Smith Approx duration: 20 mins

Cooper has mild asthma; Karen took him to the hospital for reassurance as the medication hadn't resolved his symptoms.

> *"..he was just a wheezing when we were out bushwalking…. and I had my Ventolin with me and ended up giving him a puff" "..it was getting worse as the night went on, and then I started thinking I'd better get it checked out, just mm in case it was a big one."*

There had been some conflict over the diagnosis; he also has sleep apnoea and behaviour issues,

> *".. he had sleep apnoea….. I had to go to Sydney to an assessment centre for developmental delays and learning problems that he has. Doctor there sort of said he hasn't got asthma and you shouldn't be really be giving him stuff, so I had conflicting information from different people."*

Karen said they had huge problems trying to resolve these issues until he had a tonsillectomy and everything settled.

> *"he was being treated by CPAP, and it was an absolute nightmare, I've tried to get the pressure right, it seemed to help for awhile, then he went backwards and we had behaviour problems and all sorts of things because of that." "…he had his tonsils out, the doctor originally was really reluctant to do it, saying that it won't help and well the problems won't go away… but we haven't looked back."*

Karen has asthma

> *"…being asthmatic myself"*

She has a good understanding of asthma as evidenced by recognition of symptoms, early and appropriate intervention and acceptance of the diagnosis.

"it was actually me who realised he was wheezing" "he seems to get it seasonally too" "I don't like to have him on medication all the time…as he starts to get a few wheezy symptoms I'll put him on it" "it took a while for me to believe Cooper had it as well"

Generally she feels confident in her ability to manage asthma but often questions and challenges herself to make sure.

"being aware of your own symptoms and being able to tell when things are not working" "most of the time I feel confident, like I said before I'm a worrier anyway ...am I doing the right thing"

Karen had participated in some asthma education through her work as a pre-school teacher. This information from the researcher's field notes.

Reason for non-attendance:

"I'd just started my new job and I just went aagh I've got no time. Basically, yeah, that's what it was about, and I thought… and I also said to her that if I felt I needed more help, if things were out of control I would get back in touch with her."

Interview Two

Date: 1st July 2004 Time: 0930

Interviewer: Heather Smith Approx duration: 40 mins

Jayden had been unwell for the previous twelve months and was repeatedly diagnosed with bronchitis.

> *"Jayden had been sick for nearly ooh about a year and I just kept going to my local doctor here and he just kept saying it was bronchitis"*

Eventually he had a severe episode overnight, Susan, his mother, woke in the early morning to find her son in respiratory distress.

> *"that one particular night he had coughed and coughed all day"*
> *"it was just horrible, he was just like* [mother makes wheezing sound], *he could hardly breathe. It wasn't, his lips weren't blue but they were quite, yeah very pale. Yeah, he just wasn't normal so we called an ambulance."*

Jayden was diagnosed as having asthma upon admission to hospital

> *"the ambulance officer said I think that's an asthma attack……. as we got to the hospital they said yes it was an asthma attack."*

Susan appeared both frustrated and bewildered (raised voice, tone, and body language conveyed her frustration) at his misdiagnosis (her interpretation)

> *"I actually went off at the paediatrician in the hospital and I said why was he calling it bronchitis, when I mean this could be dangerous, I mean I just wasn't aware." "he looks a lot better, instead of having sunken eyes, I mean he just looked really really sick for the last year." "I said why would the doctor keep calling it bronchitis, it really was strange, looking back now he was sick for a year."*

She was relieved that finally this was a diagnosis she felt she could do something about.

> *"I found the nurses in the hospital were just fantastic and I learnt a lot from staying there with them and then we went to the paediatrician and he said just to keep him on the Ventolin ever so often." "I've actually gone yesterday to get his*

third asthma visit, I'm really grateful for it" "I know what to look for now so we're on top of it"

Susan was very receptive to the self management strategies and has embraced change in many areas.

"they showed me how to use the puffer properly…like with the spacer and they said six puffs" "So I went back to the doctor and he said yes we'll have to put him on preventer." "I'll check for myself does he really need it all. So I cut down one dose and I noticed he started coughing again." "I think I monitor him a bit better now." "There's strictly no smoking inside."

She speaks of huge improvements in her son's general health and confidence in her ability to cope with his asthma symptoms.

"He's put on a bit of weight and he looks a lot better." "Jayden's is more exercise induced asthma, I do know all his triggers now." "if he had another episode I would know now, and I will also know I am more competent now"

Reason for non-attendance:

"Basically because, well you see I don't drive and my husband had the car…usually if I can't get my husband to drive then I get my father-in-law, well he was sick…so I sais I can't do it, so I rang the lady and said I can't make it and then virtually one or two days apart Barbara was coming up here to the doctors, so I said look is it the same thing because if it's not I will make the effort to come and see you…"

Interview Three

Date: 21st July 2004 Time: 1100

Interviewer: Heather Smith Approx duration: 40 mins

This family have five girls; all with asthma.

> *"All my other girls are asthmatics including myself." "the three of them are bronchial asthmatics so therefore they don't get asthma unless they've got bronchitis…Rebecca and Lauren are both pretty bad asthmatics, including myself"*

I interviewed both parents, Rob was on a disability pension for chronic back pain, Liz also receives a pension. They often rely on the ambulance service to troubleshoot.

> *"When we have the blackouts we usually end up having the ambulance here for Lauren more than anyone else because the machine doesn't work" " We usually order an ambulance for a certain time of night, unless it's urgent, last time we had an ambulance here, what three weeks ago, yeah it was urgent so they came straight away." "The last emergency when she went to hospital we had to call an ambulance because she went quite blue."*

Asthma has a huge impact on their lives, they attempt to normalise the situation.

> *"Rebecca, Lauren and myself we probably have three to four bouts in a week, that's a lot. Rebecca is excessively on the machine, especially during winter. She hasn't been off the machine in the past six or seven weeks." "Really our lives are full of Ventolin, preventatives and steroids, it's a normal thing, it's like getting a cup of tea."*

She is concerned that Rebecca is frequently unwell

> *"This has been the worst time for her, the last month antibiotics have done nothing for her." "We are just clueless at the moment because she is just so bad." "At the moment I'm not in control and that worries me, for the first time in Rebecca's six years I'm not"*

Liz and Rob want to allow their children to do normal things like play outside and jump on the trampoline and then they deal with the consequences.

"I can't treat her any differently, she's a child, she needs to get out and she needs to play…if I treat her differently which sometimes I do…she doesn't like it because the other girls are allowed and she is not. And that to me is unfair." "It's almost impossible to tell a kid not to run, not to play or not to jump, and if she wants to get out there on the tramp, OK go for it Rebecca, you get out there and if you have an asthma attack we'll deal with it right there and then."

This child has multiple allergies and issues which her parents have to deal with on a daily basis.

"I can't keep the child inside, she's allergic to the environment, she's just got to get out there," "The whole school is planted out with native trees, she's allergic to the lot of them."

Reason for non-attendance:

"They couldn't tell me anything that I didn't already know. Which is the truth they sent me an asthma awareness kit which I've seen before and read before and there's nothing in it that's any different from the last time I read it two or three years ago. So what was the point in going in for a consultation…"

Interview Four

Date: 3rd August 2004 Time: 1400

Interviewer: Heather Smith Approx duration: 15 mins

Mark has mild asthma with very infrequent exacerbations which are triggered by an upper respiratory tract infection.

> *"On reflection I have to wonder if there was a bit of a respiratory infection or something happening…it really was a bit of an episode then as well"*

Trish is a health professional and feels confident to deal with asthma.

> *I realised he really was very short of breath and I could hear actually an inspiratory wheeze and he was really upset and anxious himself. I thought I should get him to hospital. I was here by myself; … I called an ambulance because that is what I would have advised anyone else to do." "his Dad has other children with a history of childhood asthma…it didn't really mean too much to me because lots of people get diagnosed with asthma and I knew he hadn't had anything bad, I've never seen him really short of breath or in an acute situation."*

Her focus is dealing with acute attacks and she is very confident in this area, even if her son stopped breathing.

> *"On that night it was a worry but I wasn't stressed. I did what I thought I needed to do…even though he was my child and I was a bit emotional, but I still felt that I had enough knowledge to know what to do. Even if the worst scenario occurred where he stopped breathing or whatever I'd know that I'd have control to do something about it. I might not be very successful if he's you know really having a severe acute episode, but I know what I need to do."*

Trish feels absolutely confident to manage her son's asthma and doesn't think he needs anything more.

> *"I'm aware of the treatment and what you should do but I don't think he is the kind of child that appears to have a need for constant type of treatment." "Although he's got a diagnosis of asthmatic I feel capable of controlling what's happening with him."*

Reason for non-attendance:

"It was just a letter that I got and I thought well although he has got a diagnosis of asthmatic, I feel comfortable controlling what's happening with him."

Interview Five

Date: 16th November 2004 Time: 1000

Interviewer: Heather Smith Approx duration: 20 mins, terminated prematurely

This preschooler named Mackenzie had many allergy related problems. She is anaphylactic to dairy products and peanuts, as well as having less severe reactions to many other foods.

> *"Mackenzie has severe food allergies and she has allergies to dust which can trigger her asthma but it triggers more her allergies than her asthma…" "…because of her allergies she's classified as anaphylactic."*

She experiences asthma symptoms as part of an allergic reaction compounded by excessive mucous production.

> *"…every morning I was giving her this she would end up with a coughing attack, not quite asthma, but all the signs that come from asthma…so it's more or less a mucous build up…"*

Mackenzie was diagnosed aged six months and is now ready to start school.

> *"That's been since she was six months old, and she is five now, that's four and a half years we have been dealing with it."*

Her mother has some previous experience, she was diagnosed with asthma when she was pregnant and remembers always being unwell as a little girl, and her eldest child also has some allergies and asthma.

> *"My eldest daughter, she had what we used to call cold induced asthma so we had a little experience of asthma then." "I wasn't diagnosed with asthma until I was pregnant with Mackenzie. I remember coughing and having troubles when I was a little girl but my doctor never diagnosed me as asthma and because I didn't wheeze I wasn't diagnosed as asthmatic…"*

Mackenzie's health problems have completely changed their lives.

> *"I hate it. I hate her allergies because it makes life very difficult. I mean we've learnt to live with them and we get around it…" "…but as for the allergies- that's*

completely destroyed our life because it has, it's the very social things, eating is a very social thing."

Helen spoke of feelings of guilt and social isolation.

"...she has a great time and it's only me who sits there and says you poor baby. Which is really hard. I feel guilty, I feel guilty for passing it on." "..they really upset me and made us change our life.."

Helen became upset and the interview was terminated prematurely although we continued to talk for some time. The researcher did not ask Helen why she chose not to attend the service. Helen was advised to seek counselling to further address her issues.

Interview Six

Date: 25th October, 2004 Time: 1400

Interviewer: Heather Smith Approx duration: 30 mins

Grace has been diagnosed with asthma for six years. She was a toddler when she had her first severe episode and was admitted to hospital. At this time her mother attended IAS self management education.

> *"Grace first developed asthma when she was two and a half, we had no other signs before that…it was a big shock she ended up hospitalised with it and it was quite a bad case of it"*

Grace has been on preventer medication and still has had some severe exacerbations over the years requiring hospitalisation.

> *"...her last major admission was when she was four." "...she's on Flixotide daily."*

Janine found the self management education very helpful, she learnt a lot and says she often recommends the service to her friends.

> *"Due to the hospital admission I did the asthma course where I learned a lot, I have a lot of friends whose children get asthma ...I tell them to get their doctor to get in contact with the asthma clinic."*

Still over the years she found gaps in her knowledge and experience and finds it frustrating that all the answers aren't at her fingertips.

> *"There's still a lot of things that I feel we weren't told…" "...it was so frustrating…no one had told me before to clear their chest"*

Janine is resourceful and watches the media and internet for material; she visits her General Practitioner regularly and always challenges him.

...I got numerous reading materials, I'm always on the internet looking at it. My doctor will tell you that I'm always asking questions." "Everything has been a battle to find out more information,"

Throughout the interview she refers to self management strategies which she has adopted and she has implemented Grace's action plan prior to presentation to hospital.

"..its just being vigilant and looking at what her triggers are and keeping on top of them." "We have a six month asthma action plan review that we do…" "She's on Flixotide daily which we have got down…. My long term plan is to get her off the Flixotide altogether." "...I'm giving two puffs of Ventolin in the morning and two before bed… that's just me keeping on top of it, she doesn't wake during the night with asthma…"

Reason for non-attendance:

"I have been before, I think I went for four weeks and we talked about it, they told me what to look for and gave me information."

7.2 Application to the Constructs of the Theory of Planned Behaviour

In the following section the findings of the interviews are presented under the constructs of The Theory of Planned Behaviour, as this provides an outline of the data within the theoretical framework of the project.

7.2.1 Behaviour

Behaviour has been defined as a specific single act or collection of actions (Ajzen & Fishbein, 1980; Ajzen, 1985). The behaviour of primary concern to this project is attendance at self management education for parents or carers of children with asthma.

The desired behaviour for this population is attendance at self management education; each of the participants interviewed had declined an invitation to attend self management education. However despite non attendance, evidence of self management and best practice existed in the findings. Self management behaviours have previously been identified as central to the achievement of best practice in asthma management under the guidelines of the National Asthma Council's Six Step Plan. Strategies included using preventer medication, monitoring symptoms, avoiding triggers and implementing action plans (Dinwiddie & Mulie, 2002; Kolbe, 2002).

This quote provides evidence of a number of best practice behaviours by the participants including adoption of Step Three, identify and avoid triggers, the child's trigger is seasonal changes. Monitoring of the child's symptoms and increasing and decreasing his medication

dose in response to the symptoms is relevant to Step One, assessing asthma severity, Step Four, maintain best lung function and Step Five, develop a written action plan.

> *"... he sort of seems to get it seasonally too, coming into winter, so I don't like to have him on the medication all the time, he takes Flixotide... what I do is you know he sort of takes it, - as he starts getting a few wheezy symptoms I'll put him on it and then okay say towards the end of ……. I don't know six months or whatever he's usually on it, I can't remember, but then I take him off it and see how he goes but he usually doesn't need to stay on it all the time."* (Interview 1.)

These responses relate to Step Three, identify and avoid trigger factors.

> *"You know I haven't actually cleaned today its filthy this morning. But usually, usually I vacuum clean and make sure everything is wiped over so there's not too much dust and that sort of thing."* (Interview 2.)

> *"...its just being vigilant and looking at what her triggers are and keeping on top of them."* (Interview 6.)

In the following quote is evidence of Step Five, develop a written action plan, and a suggestion that this child is also being reviewed regularly by her doctor as recommended in Step Six.

> *" My doctor will tell you that I'm always asking questions. I've always got something to ask, ...we have a six month asthma action plan review that we do"* (Interview 6.)

Confidence to implement self management behaviours is also an important consideration (Aroni et al, 2003; Milnes & Callery,2003), and is evident in some degree in the quotes above, the following comment is very clear.

> *"if he had another episode I would know now, and I will also know I am more competent now"* (Interview 2.)

There was evidence of reinforcement of these strategies from a range of health professionals including asthma educators, hospital staff and medical managers. Positive

outcomes in this group included recognising deterioration in their child's asthma, implementing action plans, identifying and avoiding triggers.

Some self management practices implemented by participants, such as over use of reliever medication and reliance on ambulance services, fell outside the best practise guidelines outlined in the National Asthma Council's Six Step Plan and are therefore considered inappropriate practices. It would be most desirable for these participants to attend self management education to enable these issues to be explored and addressed.

7.2.2 Behavioural Intention

Behavioural intention is the immediate determinant of behaviour, and is the product of attitudes, subjective norms, and perceived behavioural control. When an appropriate measure of intention is obtained it will provide the most accurate prediction of behaviour (Ajzen & Fishbein, 1980; Ajzen, 1991). Behavioural intention is assumed to capture the motivational factors that influence a given behaviour and is indicated by the person's subjective perception and the probability that the behaviour will be performed (Ajzen, 1991).

Throughout the course of the interview each of the participants indicated in some ways that at the time of the invitation they did not intend to participate in the service being offered.

> *" I also said to her* (community health asthma educator) *that if I felt that I needed more help, if things were out of control or if I was concerned I would get back in touch with her".* (Interview 1.)

> *"it was just a letter that I got and I thought well although he has got a diagnosis of asthmatic, I feel quite comfortable controlling what's happening with him."*
> (Interview 3.)

One of the participants attended a similar service offered at her General Practitioner's surgery within a similar time frame.

> *"…and I had to say sorry I can't make it and just at that same week, Brenda I think her name was, she came here to the doctors"* (Interview 2.)

7.2.3 Perceived Behavioural Control

Perceived behavioural control is comprised of two components: perceived power or self efficacy, which deals largely with the ease or difficulty of performing the behaviour, and control beliefs, the extent to which the behaviour is seen to be controlled by the performer (Ajzen, 2002). It is determined by the individual's beliefs related to the presence or absence of facilitating factors and barriers, and their power to overcome them (Ajzen, 1991). In this project the researcher is primarily looking for evidence of the ease or difficulty of attending self management education and if the participants found this to be under their control. Also of interest are the participant's beliefs about self management strategies.

Perceived behavioural control was identified as a positive construct in self management behaviours and was evidenced by parents altering doses of preventer medication and sometimes stopping them all together

> *"I don't like to have him on medication all the time…. but then I take him off it and see how he goes,"* (Interview 1.)

> *"I sort of thought at one stage I'll check for myself does he really need it all* (drug). *So I cut down one dose and I noticed his coughing started again."* (Interview 2.)

These comments provide evidence that parents feel in control of how much medication they administer to their children and they have confidence in their ability to alter the dose as they see fit.

7.2.3.1 Perceived Power

People's behaviour is strongly influenced by their confidence in their ability to perform the behaviour; it reflects the performer's appraisal of the ease or difficulty of performing the behaviour (Ajzen, 1991; Ajzen 2002). Of interest to this research is the reason why the participants had no intention to attend the self management education. The desired outcome of self management education is the adoption of self management behaviours. Confidence to manage asthma was a recurring theme throughout the interviews, from this evidence it may be implied that these participants would not have identified a need to attend the sessions being offered.

Some respondents had previous personal experience of asthma or had learnt the necessary skills and knowledge elsewhere and reported high levels of confidence in the areas of asthma self management.

> *"...I still feel that I don't need a lot of support, being asthmatic myself kind of thing you know, I kind of know what to do, what to look for..."* (Interview 1.)

> *"I think I would know and I will also know I'm more competent now,"* (Interview 2.)

> *"I did what I thought I needed to do and it all worked out for the best."* (Interview 4.)

> *"I've pretty much got a handle on the whole situation now."* (Interview 5.)

> *"…and I was on top of it then and it's only because if I know she's going downhill and I'm not getting on top of it I'll ask the doctor for Redipred."* (Interview 6.)

One example that illustrated a lack of confidence in self management is the child with severe asthma and frequent symptoms, nearly every day; although there was evidence of knowledge, her parents had experienced limited success in controlling the episodes of asthma reflecting a negative belief in their ability at this time.

> *"This has been the worst time for her, for some reason this year. Last year she was nowhere near as bad as what it is this year. We have never had the ambulance to her like I said and we're just clueless at the moment because she's just so bad. She exerts herself in the house, she'll run from here up the hallway into the bedroom and she'll have an asthma attack"* (Interview 3.)

7.2.3.2 Control beliefs

Control beliefs reflect the extent to which the individual believes performance of the behaviour of interest is up to them. When people believe they have the necessary resources and opportunities including skills, time, money and cooperation by others they should exhibit positive control beliefs (Ajzen, 1991; Ajzen, 2002). Barriers to a positive perceived behavioural control for the person with asthma include lack of skills in self management practices, personal resources including knowledge, and community resources (Ajzen, 1991).

Knowledge and skills have been identified as a facilitator of positive control beliefs; one respondent said she knew about peak flow monitoring but said she didn't know what significance it had or how she should respond. Her response implies a negative control belief in relation to monitoring peak flows.

> *"Well I have a peak flow monitor here which ahh I haven't got a clue and I don't understand it, I don't know what I am supposed to be in measurements… don't know what any of us are supposed to be measurement wise. I use the peak flow sometimes and if I can get it over a certain amount then I'm happy."* (Interview 3.)

The following responses reflect an increase in knowledge and skills, the second response implies a control belief reflecting this parent's ability to identify and minimise exposure to triggers of her child's asthma.

> *"They showed me how to use the puffer properly…and the spacer and they said six puffs, like one puff, five breaths. Well I hadn't been doing any of that."* (Interview 2.)

> *"…we talked about it, and they told me what to look for and gave me information." "It's just being vigilant, and looking at what her triggers are and keeping on top of them."* (Interview 4.)

Transport was also identified as a barrier for one family;

> *"I did have an appointment with a lady in Nowra but I couldn't get there because I didn't have the car…and just at that same week Brenda came to the doctors and it was fantastic." "..about some asthma education. I saw her twice"* (Interview 2.)

Time and the pressure of a new job was the perceived barrier to control for one parent.

> *"I'd just started my new job and I just went aagh I've got no time"* (Interview 1.)

7.2.4 Subjective Norms

Subjective norms are also made up of two components, normative beliefs and motivation to comply. Normative beliefs are concerned with the influence of the social environment; that is the individual's perception that people who are important to them think the behaviour should or should not be performed. Approval will result in a positive subjective norm. Normative beliefs will be further reinforced where the person is motivated to meet the expectations of significant others, that is when the individual cares about what others

think, and there exists a motivation to comply (Ajzen & Fishbein, 1980; Ajzen 1991). Social support, family relationships and relationships with health professionals have previously been identified as important in the adoption of self management behaviours (Kyngas &Rissanen, 2001; Ankney et al, 2001).

There is evidence of social pressure from health professionals and the wider community to prevent children with asthma from being exposed to cigarette smoke (McQuaid et al, 2003), the following quote reflects a subjective norm to support this behaviour.

> *"All our friends know as well so there is strictly no smoking inside…Well yes too all of my friends, well I've never liked them in here smoking anyway. But now I say outside and that's it"* (Interview 2.)

7.2.4.1 Normative beliefs

A normative belief is an individual's perception or belief of what they believe significant others in their life believe they should do in relation to the given behaviour (Ajzen, 1991). Within the transcripts are comments which illustrate the participant's normative beliefs about some self management behaviours.

> *"So I thought that um, yeah, I should get him to hospital and I was here by myself so. I used to be an ambulance officer, and his Dad is an ambulance officer even though we don't live together. So yeah, that's what I did …"* (Interview 4.)

This comment suggests that this parent's action would be supported and approved of by the child's father.

Children spend a significant part of their day at school and the school may be seen as important. Several respondents made a reference to their children's school. The following

comment reflects a belief that the school will respond appropriately to an asthma related incident.

> *"His pre-school and when he goes to school next year, his school will know…so I know that if ever he is in a spot they will know what to do."* (Interview 2.)

The next comment also suggests the school is a significant influence in this child's life; however, these parents believe the school should be more helpful in managing their daughter's asthma.

> *"the school just gets upset if she comes up more than twice a week and that's silly because they know that she's got severe asthma and she needs her medication. …the school's got to help us out, we can't keep her home. It wasn't very pleasant at the school; they get a bit testy I think."* (Interview 3.)

All of the participants volunteered comments or appraisals of their chosen medical manager; support, positive relationships and effective communication with health professionals has been identified previously as a means of improving self management (Sawyer, 2002; Fielding & Duff, 1999). Generally there were comments which portrayed sentiments of faith and confidence in their doctors. Relationships between the medical manager and the children with asthma and their families are considered to be important as the medical manager is one of the key and legitimate providers of advice regarding the management.

> *"We've got it down to QVAR 50, I've just actually gone yesterday to get his third asthma visit." ".. especially now that I've got the plan, and the doctor on the plan, it's written down. What we do now, if it gets worse and then a severe case, that's reassuring too."* (Interview 2.)

> *"I mean she's got a good doctor, and she manages pretty well doesn't she."* (Interview 3.)

> *"The doctor put it down to an acute episode due to a respiratory tract infection and I believe that was the case because he's never really had another episode."* (Interview 4.)

"Our family doctor is brilliant, I am really really happy with her, our immunologist in Sydney is lovely as well. We did go to another hospital in Sydney who we stayed with for about a year and then left because they were sending me skitzy with all the information, they were really freaking me out. ...there was another hospital that was really supportive and brought us back to mainstream life and told us to go live…" (Interview 5.)

"...from there we have maintained the same doctor…he's been wonderful." (Interview 6.)

7.2.4.2 Motivation to comply

This construct relates to being motivated to do the things that relate to our normative beliefs; that is, motivation to do the things the performer believes people of significance to them think they should do in relation to a given behaviour (Ajzen, 1985; Ajzen,1991). This was not asked directly of the participants in the interview process and there are limited responses from the participants within the transcripts.

Previously the doctors have been identified as people of significance and there is reference to this in the transcripts indicating a motivation to adhere to the doctor's advice.

"we went on for a couple of years trying to get the treatment right" (Interview 1.)

One of the participants implies motivation to comply with the belief of her friends and health professionals, that her son should not be exposed to environmental tobacco smoke through the following statement:

"if we go to my mother in laws now and they are all sitting there chain smoking. Well we all just go and sit outside now. No he's not going to sit in there, we all go outside and I make them." (Interview 2).

The following comments portray a strong motivation to comply but from the transcripts it is not clear who the person of significance is.

> *"Yeah, well we are talking about my child's health So you've got to…you've got to do it."* (Interview 2.)

And later in the transcript

> *"At the hospital I just got an attack of the guilts, because I thought why didn't I pick this up earlier…I just never wanted to feel like that again. I got as much information as I possibly can"* (Interview 2.)

7.2.5 Attitude

Ajzen (1985) defines attitude as the individual's salient beliefs about outcomes or attributes of performing the behaviour, which is then weighted against the evaluations of those outcomes and the value attached to them. The two constructs which determine attitude are behavioural beliefs and evaluation of the outcome. Of interest to this research is attendance at self management education and also the parents' attitude towards the diagnosis and impact of asthma.

A respondent had attended the IAS previously and found no improvement in her child's symptoms. As the interview with this family proceeded it became evident to the researcher that this child has severe and unstable asthma.

> *"This has been the worst time for her for some reason this year… She exerts herself in the house, she'll run from here up the hallway into the bedroom and she'll have an asthma attack. That's quite severe. She's on the highest preventative you can give her."* (Interview 3.)

> *"There's nothing really much changed, you know it's the same thing. Well what do you give your child, how often do you give it blah, blah, blah and it doesn't change anything in the household…"* (Interview 3.)

However, they believed they had embraced the recommendations of both their doctor and the asthma educator. Their coping skills had become crises management interventions with limited success thus reinforcing their attitude that self management skills were not effective.

7.2.5.1 Behavioural Beliefs

Behavioural beliefs are determinants of attitude, and are established by the individual's salient beliefs about the outcomes or attributes of performing the behaviour (Ajzen, 1991). Behavioural beliefs have been identified within the transcripts firstly in relation to attendance at self management education and secondly, in relation to adoption of self management strategies. The following quote reflects a salient belief that the service was available to this family and that the advice is reliable.

> *"It was good to know there was someone there…someone there that is qualified to answer my question and who knows everything about it."* (Interview 2.)

One respondent had not previously attended; she spoke generally about exposure to information and learning in a positive light.

> *"There's always opportunities to learn about stuff, you don't know everything."* (Interview 1.)

Another respondent was uninterested as she believed herself to have all of the resources and answers she needed, already self sufficient. This child had occasional exacerbations which the mother was able to cope with competently, the following quote illustrates a salient belief that no further intervention or behaviour change is necessary.

> *"it was only those couple of times that it affected him. And he's been quite an active boy, like he runs around quite a lot so… I can't say its, I'm aware of the*

treatment and what you should do but I don't think he's the kind of child that appears to have a need for constant type of treatment." (Interview 4.)

7.2.5.2 Evaluation of Outcomes

This construct refers to an evaluation of the outcomes or attributes of performing the behaviour. Positively valued outcomes of performing the behaviour will contribute to a positive attitude to that behaviour (Ajzen, 1991). Some respondents who had previously attended self management education made positive evaluations of the service.

"...she was really helpful." (Interview 2.)

"Due to the hospital admission I did the asthma course where I learned a lot, I have a lot of friends whose children get asthma ...I tell them to get their doctor to get in contact with the asthma clinic." (Interview 6.)

A respondent who had also previously attended sees no benefit in revisiting an asthma educator and made strong statements about her evaluation of the service on two occasions. These statements refect a negative evaluation of the outcome of attending self management education.

"They couldn't tell me anything that I didn't already know. Which is the truth, they sent me an asthma awareness kit which I've seen before and read before and there is nothing in it that's any different from the last time I read it two or three years ago. So what was the point in going in for a consultation" "What information she has given me is not going to change anything that I do, because I already do a lot." (Interview 3.)

"...and give her this, help her with this and keep her away from foods that she is allergic to... I'm doing all that anyway; yeah it doesn't make a difference." (Interview 3.)

7.3 Support

Support was a recurrent theme throughout the interviews and has previously been identified as a required resource to promote adoption of self management behaviours; support may include encouragement, rapport building, positive feedback and emotional support (Kyngas & Rissanen, 2001; Mahli, 2001). This emergent theme from the transcripts of the interviews was not applicable to the Theory of Planned Behaviour because it was viewed by the researcher as falling outside the constructs of the theory.

Within the transcripts there is evidence of support from families as seen in the following quotes

> *"My Mum's pretty good with the kids, she knows how to feed Mackenzie which is always handy." "...the supports great, everyone is, my family is very understanding, and we go to friends and try to make it really low key."* (Interview 5.)

and

> *"my husband, myself, his brothers, so they sort of, they are aware."* (Interview 2.)

While another family relayed an absence of support

> *"we had no support, we were living on our own"* (Interview 3.)

and later in the transcript

> *"Rob went in the ambulance and I waited at home with the other children"* (Interview 3.)

Support may also be evident within the wider community. One of the participants portrayed a sense of belonging within their community and the feeling that people are all on her son's side.

> *"It's amazing how many people respect your wishes" "We're lucky we live in a good little community and I do have a lot of support."* (Interview 2.)

This concludes the key findings from the transcripts of the interviews. The majority of themes related to the constructs of the theory. Support was the only emergent theme which fell outside the Theory of Planned behaviour. In the following chapter issues arising from these findings will be discussed.

8 DISCUSSION

In this final chapter the key findings of this project are discussed and the main research issues considered in the context of current literature. The aim of this project was to investigate why parents or carers of children with a diagnosis of asthma chose not to attend self management education. Major themes are presented which emerged from the research participants' transcripts that help to explain why families may have made the choice not to attend the available services. These include the themes of self confidence, attitudes towards self management education, experience of asthma, support, skills and knowledge. Finally, the limitations of this research project are discussed and recommendations made in relation to meeting the further needs of the participants and the improvement of health services.

8.1 Themes

In the following section the major themes emerging from this research project are presented with comments about how these findings relate to current literature and to the provision of the self management education service. The majority of themes are applicable to the conceptual framework of the thesis, Ajzen and Fishbein's Theory of Planned Behaviour (1980) and are discussed in relation to the constructs of the theory. Where it is not pertinent to the theory the theme is discussed in relation to the findings in the literature. Emergent themes applicable to the Theory of Planned Behaviour include:

- Self confidence
- Attitudes towards self management education
- Experience of asthma
- Confidence in medical managers

- Parental responsibility
- Skills and Knowledge
- Transport
- Time

The remaining theme which fell outside the constructs of the theory was support; support was raised by a number of participants and is an important consideration, it does not relate directly to the determinants of behaviour change identified within the Theory of Planned Behaviour. The themes are discussed in order of their occurrence in the transcripts.

8.1.1 Self Confidence

Parents self confidence in their ability to manage their children's asthma was the most dominant theme throughout this research. Most of the respondents either expressed that they felt that at the time of their invitation to attend self management education, they had the self confidence to self manage their children's asthma, or they reported a huge increase in self confidence following the self management education provided at the General Practitioner's surgery. This was highlighted by participants' indications that they believed themselves to have adequate knowledge and skills and reported improvements in the lived experience of asthma following self management education. Each of the participants interviewed generally believed themselves to be managing their children's asthma well in that they felt they were able to recognise when their children were unwell and take some action to remedy the situation. Self confidence to manage asthma can be interpreted as perceived power; in this situation the ease of adopting self management behaviours.

Perceived power has been previously defined as the perceived ease or difficulty of performing the behaviour and is a construct of perceived behavioural control from the Theory of Planned Behaviour (Ajzen, 1991), as such it has not been raised in the transcripts in relation to attendance at the service on offer; however, there is evidence of a positive perceived power in relation to self management and this may be significant. Self confidence implies that the person has no identified unmet needs and therefore from this information we can deduce that high levels of self confidence would make the participants believe there was no need for them to attend the service on offer; however, this explanation is not supported in the literature.

The findings of this research suggest that self confidence by parents and carers of children with asthma may not always reflect adoption of best practice in asthma management. For example, two of the families talked about crisis intervention as their main self management intervention. Best practice as outlined in the NAC Six Step Plan would recommend recognising an early deterioration in symptoms of asthma, implementing the written action plan and avoiding triggers as a means of avoiding the need for crisis management (National Asthma Council, 2002).

This evidence would indicate that self confidence should be a key issue to be identified by service providers of self management education at the first telephone contact with the parents or carers. It has previously been identified that self confidence does not always reflect best practice and a capability to self manage asthma. The endeavour is to identify who are implementing best practice and those who may benefit from self management

education. The challenge for the service providers is to engage with these families who may benefit from the self management education service and provide a non judgmental and safe environment where best practice can be promoted.

8.1.2 Attitudes towards self management education

Several of the respondents in this study population have previously attended self management education either with the Illawarra Asthma Service (IAS), or other health facilities, and from evidence within the transcripts the researcher was able to identify attitudes towards self management education. Attitudes to self management education were identified in both positive and negative perspectives and this may impact on the individual's decision to attend or not attend the service offered. Ajzen (1985) defines attitude as the individual's salient beliefs about outcomes or attributes of performing the behaviour, which is then weighted against the evaluations of those outcomes and the value attached to them. The two constructs which determine attitude are behavioural beliefs and evaluation of the outcome.

There were a range of positive comments within the transcripts which relate to the usefulness of self management education and evidence of the adoption of best practice strategies in self management of asthma. As a result of these attitudes participants indicated they were not likely to attend the service every time it is offered because they had, on previous access to education, acquired what they believe to be adequate knowledge and skills. Their comments also suggest a high level of self confidence which was earlier identified as a contributing reason for non-attendance.

There were also a range of responses which are equally negative, where the participants feel the service has not helped them to manage their children's asthma and the service providers have nothing new to offer them. The participants also indicated that they did not attend because they believed the added benefit to be insignificant in that they are doing everything they can to minimise the impact of asthma on their families life. These responses reflect the beliefs of the participants based on their evaluation of the negligible outcomes gained from attending self management education.

One of the participants who viewed the service in a negative light also made reference to an information package; the participant had a negative attitude towards the package describing it as unhelpful, the information having been provided to her on a previous occasion. The literature relating to self management education consistently supports this participant's view that information alone is not effective. Recommendations coming from the literature suggest that information is a basic requirement but it is the relationship between a health professional and client that is the most effective in establishing behaviour change (Blessing- Moore, 1996; Bauman et al, 2003).

These findings further reinforce the wealth of literature which recommends that health providers should aim to engage with, and develop relationships with, their clients; relationships which foster trust, include interactive conversation, and identify client concerns and goals; these attributes are seen as instrumental in bringing about behaviour change (Sawyer, 2002; Fielding & Duff, 1999; Bauman et al, 2003; Aroni et al, 2003). Engagement with families has been identified in the literature to be not well achieved, with

parents of children with chronic illness describing situations where health professionals were unwilling to share their power and failed to listen to parent's viewpoints and failed to recognise parent's expertise (McCarthy et al, 2002; Kieckhefer & Ratcliffe, 2000). The literature relating to self management education promotes an intervention which focuses on the experience of living with asthma, and enables families to develop the skills and attributes required to make informed choices about their health and to competently manage their asthma, strategies may include direct experience, observational learning and the presentation of knowledge in an environment conducive to learning (McCarthy et al, 2002; Weeks et al, 2003, Kralik et al, 2004).

Comments by the some of the participants reflect a belief by them that the service is readily available when they identify a need or concern and that they will receive reliable information as they need it. This implies a salient belief about the effectiveness and availability of the service. Behavioural beliefs are determinants of attitude (Ajzen, 1991). As participants have a need or a concern they indicated they would contact the asthma service for an appointment or telephone advice; this may have influenced their decision not to attend at the time of invitation because once again they felt self confident in their ability to self manage their child's asthma and to find help when it is needed.

8.1.3 Experience of asthma

In the literature self management activities were presented as a means of living with a chronic illness; personal experience of illness was identified as an important factor in how

self management was adopted (Kralik et al, 2004; Aroni et al, 2003). These issues relate to past experiences which influence a persons' perceived power; perceived power is a component of perceived behavioural control under the conceptual framework (Ajzen, 2002). In the findings a clear picture of how different each of these families experience of asthma and subsequent self management was illustrated. From the sample population a number of the children had relatively mild experiences of asthma and others experienced severe asthma with symptoms on most days. Each of the parents interviewed verbalised the diagnosis of asthma as having an impact on their lives, all of them spoke of an episode in the past that had caused them to feel emotions ranging from concern to fear. The ongoing impact this had on their lives has varied greatly and seems to be influenced by the frequency and severity of episodes of asthma, self confidence of the parents to manage the symptoms and to some degree other health issues, such as recurrent tonsillitis. The transcripts demonstrate a range of responses; some families have implemented best practice guidelines and have found a significant improvement in asthma outcomes for their children.

However for one family the outcomes were less favourable in that they were constantly reacting to acute episodes on an almost daily basis with limited or no overall control. The literature would suggest this lived experience would reinforce their belief that nothing they did would improve their child's asthma (Kralik et al, 2004; Weeks et al, 2003).

Where participants experience benefits from adopting a successful strategy, their perceptions of self efficacy, control and empowerment increase and they are more likely to

apply these skills again (Weeks et al, 2003). The responses from the participants in this study indicated that a lack of these attributes resulted in their adoption of ineffective behaviours in the management of their child's asthma. This scenario presents a difficult challenge for the provision of asthma management services; the literature consistently promotes the use of effective communication, partnerships and a focus on health promotion and healthy lifestyles to provide an environment where self management strategies can be adopted (Bauman et al, 2003; Aroni et al, 2003).

However, the transcripts have provided evidence that suggest it would be quite difficult to engage with families who have low levels of perceived power and for them to agree to an appointment where these strategies would be employed. Negative beliefs and attitudes of parents and carers of children with asthma present barriers to the provision of asthma self management education services in that they are not likely to commit to participating in a service which they believe to have no benefits for them. The literature proposes that behaviour change is more likely immediately following an acute exacerbation of asthma symptoms (Buston & Wood, 2001; Dinwiddie & Mulier, 2002); service providers should concentrate their efforts at this window of opportunity and adopt an approach which is motivational and identifies discrepancies between client goals and current client behaviours.

8.1.4 Support

Support was also a recurrent theme throughout the transcripts; it was the one theme that did not fall within the constructs of the conceptual framework but has been included here

as it presented as a dominant theme in the transcripts. Participants referred to support from a range of people, including their immediate and extended families, their doctors and the wider community. Those participants who made positive remarks about the level of support they received had previously attended self management education and have been able to make significant changes in their behaviour to better manage their children's asthma. Participants who felt they had little support expressed they were having some difficulties managing and coping with their child's symptoms of asthma. The literature would support this finding as it strongly recommends identifying and enlisting the help of key support people in the process of changing behaviour to facilitate self management as part of best practice guidelines (Kyngas & Rissanen, 2001; Weeks et al, 2003). Asthma self management education services may be able to provide support on some levels through the fostering of a respectful and trusting relationship where the clients are able to contribute their experience and concerns in living with a child with asthma.

Support was also a determinant of attendance at self management education; those families that expressed an absence of support also expressed a belief that the service was not helpful to them in the management of their children's asthma. This includes both support from the service and general support from families and communities. Where families felt supported they had also attended self management education and expressed positive experiences with improved knowledge, skills and self confidence. Support has been viewed as an indirect factor to determine attendance in that it impacts on perceived power. The literature recommends identifying key people and enlisting their help (Kyngas & Rissanen, 2001; Weeks et al, 2003), in this way it may become easier to perform the

behaviour in question, attendance at self management education, through increasing the effort, removing obstacles and sharing the experience with others.

8.1.5 Confidence in medical managers

A further construct to determine intention within the Theory of Planned Behaviour is subjective norm, which is comprised of normative beliefs and motivation to comply. Normative beliefs are concerned with the influence of the social environment (Ajzen, 1985; Ajzen, 1991), the parents relationship with their medical manager is a normative belief.

Throughout the literature pertaining to best practice in asthma management the medical manager is portrayed as a person of significance; the importance of a relationship built on trust and shared communication has been identified as a priority (Goeman et al, 2005; Aroni et al, 2003). Each of the participants referred to their doctors and implied that they felt confident in their management of the children's asthma. This may reflect a situation where the participants felt that they were receiving adequate guidance and support from this source. Survey evidence from the 1991 National Health Strategy indicates that most people are satisfied with the support and advice given by their General Practitioner (Grbich, 1996). Health in Australia is in the majority driven by medical discourse and culturally the doctor is perceived to be expert in the delivery in health care (Grbich, 1996), this may be a contributing reason as to why people trust their doctor to meet their needs and do not routinely look elsewhere for advice. It has been the experience of the IAS that very few General Practitioners refer their clients for asthma education; this may imply that

they also are not promoting the service to their clients with asthma. This finding reinforces the need for asthma education services to work in conjunction with General Practitioners and to actively promote the benefits of the service to their clients.

8.1.6 Parental responsibility

It is proposed that within this study's population the parent child relationship would have some bearing and would influence the decisions parents make in relation to a whole range of behaviours. In five of the six transcripts there is some evidence of motivation to comply with an expectation that parents will provide appropriate care for the children involved. Behavioural beliefs are further reinforced where the person is motivated to meet the expectation of significant others, motivation to comply (Ajzen & Fishbein, 1980). This is most evident where the participant refers to feelings of guilt and her motivation to do something about it because it is her child's health at stake and to a lesser degree the participant who presented to hospital to make sure her assessment of the situation had been accurate. There is also some evidence within the transcripts of behaviour change which can be attributed to motivation to comply with providing care for the children involved, an example is the family adopting a range of strategies to prevent exposure to environmental tobacco smoke. Overall this parental responsibility may be viewed by the participants as fulfilled by their current practices and the advice they are receiving from their doctor as it has not influenced them to attend the service offered by the asthma educators. Several studies (Horner, 1997; Trollvik & Severinsson, 2004; Dalheim Englund et al, 2001) have identified the period prior to the diagnosis of asthma as the most difficult for mothers and families with expressions of uncertainty, fear and frustration. Further to this, diagnosis

provided a sense of relief and changed an overwhelming experience into a manageable one. In this study population only one of the children was diagnosed at this presentation to hospital and this family sought self management education from an alternative service provider. All other participants had been diagnosed with asthma for some time and had sought information and advice from a range of other sources. It is a further recommendation from this evidence that asthma self management services should target people newly diagnosed with asthma and their carers.

8.1.7 Skills and Knowledge

Skills and knowledge are also significant components of a person's control beliefs in relation to the adoption of self management strategies. The skills required by the person with asthma or their carer include recognising deteriorating asthma, monitoring of symptoms or peak flow readings, and understanding of the written action plan (National Asthma Council, 2002). These skills provide the person with asthma or their carer with some control over the implementation of self management behaviours and have also been previously identified as necessary resources to improve adherence in a number of self management areas (Bauman et al, 1992; Kolbe, 2002; Dinwiddie & Mulier, 2002). The appropriate choice of device and correct technique using the device are also essential skills to achieve satisfactory delivery of the drug to the airways; this in turn impacts on the effectiveness of the drug and may influence a parent's attitude towards the use of that drug. One of the aims of self management education is to improve skills and knowledge so parents and carers can make informed decisions about asthma management.

The participants in this research project generally report favourable self assessments of their skills and knowledge, in that they feel that they understand their children's asthma, they report recognising when their children are becoming unwell and have some strategies to deal with the situation. In these ways the participants are demonstrating that they believe themselves to have some control over the management of their child's asthma.

Once again this finding would indicate that skills and knowledge should be assessed at the first point of contact by the service provider to identify those clients that may benefit from an intervention to promote best practice in this area of self management.

8.1.8 Transport

Lack of transport was perceived as an issue for one family, this is categorised as a control belief because access to transport was thought to be a necessary resource to complete the behaviour in this study (Ajzen, 1991). Transport has been identified in other studies as a significant contributing factor to facilitating attendance at clinic appointments (Lacy et al 2004; Griffin, 1998). On this occasion this family were able to access an asthma educator at their local doctor's surgery to overcome their lack of transport. Community asthma services are able to provide a home visiting service, resulting in the issue of transport being addressed by the service provider; this aspect of the service needs to be communicated to the clients to effectively overcome this barrier.

8.1.9 Time

Time was also identified as an issue; as with transport it is a necessary resource to complete the behaviour in question and therefore a control belief (Ajzen, 1991). Time has been identified in other studies and specified as inconvenience of attending an appointment and difficulty in obtaining time off work (Dyer, Lloyd, Lancashire, Bain & Barnett, 1998; Griffen, 1998). Time could be seen as an issue when it is difficult for clients to make an appointment within the constraints of the available clinic times, or perceived. Time may be related to other constructs that have contributed to the parents or carers not using health services. This may include self confidence, attitudes towards self management education, or skills and knowledge. A person who feels a lack of self confidence and acknowledges a need to learn more about their children's asthma may be more likely to be committed to prioritise and allocate the time required to attend the services offered. The participants of this project all reported high levels of self confidence in their ability to manage their children's asthma so it is not unexpected that they did not prioritise the time to attend.

In this study population many of the participants have adopted self management strategies in accordance with best practice, it is the responsibility of the service provider to identify at the first contact those families that would benefit from self management education and encourage them to attend.

8.1.10 Intention

Within this study population, the Theory of Planned Behaviour has provided an insight to the participants' intention to attend self management education. From the results presented

in the previous chapter the researcher can state with confidence that the participants had not intended to attend the self management education sessions offered by the IAS, and this intention was predictive of their behaviour; that is they did not attend the service offered at the time of referral. Two of the participants had previously attended the IAS self management education, one participant received advice from a nurse at her General Practitioner's surgery, and a fourth had attended self management education at another hospital. Only two participants had received their information from other sources; one was a health professional and the other had received some in-service on asthma management in her role as a preschool teacher.

Application of the construct of intention has accurately predicted the participant's behaviour in this study, however, from discussion of the constructs of intention this research has identified that participants may have benefited from the education service in some areas of asthma self management. Assessment and communication skills of the service provider have been identified as key issues in recruitment of parents and carers to attend the service.

8.2 Limitations of the research

It is now relevant to present the limitations of this research project which include issues related to the recruitment process and the methodology used to complete this project.

8.2.1 Recruitment

Sampling bias is an unavoidable difficulty in this study. Parents and carers of children with asthma can only be invited to participate and although the response rate was considered quite acceptable at nine percent, their response to the invitation may demonstrate an interest and motivation in the asthma management of their child. It was anticipated by the researcher that response rates would be relatively low as this population had already declined an invitation to attend self management education. The researcher is unable to draw any parallels or conclusions to the remaining ninety one percent of parents or carers invited to participate. These results have poor generalisability, as this research has only reached a small group of the total target population.

A further issue related to recruitment of participants was that four of the six participants had previously attended some kind of self management education and in fact two of these had attended the Illawarra Asthma Service. This situation was unavoidable as children with asthma may have multiple referrals to the service and the researcher was only provided with replies to the invitation extended by Illawarra Area Health Service. The experience of these participants remains valid to this research and is significant for consideration of service provision by the asthma educators working with this study population. This aspect of the study once again provides poor generalisability.

There is also some inherent bias and inequality in the interview due to the relationship of the researcher and the participants. The interview situation has been instigated by the researcher to further promote and foster an interest in learning about a phenomena

(Minichiello et al, 1996), in this instance non attendance at asthma self management education. The invitation to participate in the research was extended by Illawarra Health; some clients may have perceived an obligation to respond to maintain their relationship with the service provider, likewise some may have declined to participate because Illawarra Health was their service provider. This issue was addressed in the presentation of the Information Sheet and the Consent to Participate (Appendix One & Two), participants were assured that their participation had no bearing on their current or future relationships with the Illawarra Asthma Service.

8.2.2 Methodology

The research methodology requires that the interviewer establish a rapport with the participants to facilitate communication that will be meaningful to the research and allow for some understanding and interpretation of another persons reality of their situation and needs (Minichiello et al, 1996). The interviewer has extensive experience as a community health nurse and in asthma education and brings to this situation well developed inter-personal skills, expertise and knowledge in the area of asthma and understanding of primary health care. This situation has both advantages and disadvantages. The participants were made aware of the researcher's interest and background and this may have influenced the way they responded to the interview questions and to the researcher. Some of the participants had very positive relationships and past experiences with the health system and asthma educators while other participant's experiences had been more negative. An advantage was that during the process of conducting interviews many issues were raised and the interviewer found it necessary to draw on that experience and knowledge to

provide appropriate responses and feedback. This may also be viewed as a disadvantage as the researcher may have experienced difficulties disengaging from the role of educator and health professional.

There is also an element of social responsibility restricting responses to some degree. As previously identified the parent child relationship is worthy of consideration, it is expected that parents will adequately meet the needs of their children including providing adequate health care. Parents were aware of the interviewer's background in health and asthma education and it would seem reasonable to assume that they would try to portray themselves in a positive light.

The choice of semi-structured interviews has adequately met the needs of this research project. It has provided a rich source of data relevant to the reasons why the participants chose not to attend the service being offered to them. The aim of the researcher was also to gain an understanding of each of the participants' experience of living with a child with a diagnosis of asthma, and to explore their beliefs about the service that had been offered to them, this has also been achieved on some levels. This area of interest could have been explored in much greater detail but was not the primary focus of this project; it did however provide some further understanding and appreciation of why the participants chose not to attend the service. This leads to an evaluation of the questions used within the semi-structured interview. The responses and data collected are somewhat limited by the

questions that were asked of the participants and those that could have been asked and were not.

8.3 Recommendations

The response rate to this research project was only nine percent and yet approx 66% do not attend education. All of those that responded have demonstrated some interest in the asthma service so it is hardly surprising to find that the respondents have a high level of self confidence to self manage their children's asthma. In recent months Community Health has implemented a new data base, Community Health Information Management Enterprise. This data base provides the service with an opportunity to appraise the reasons why a referral does not proceed to an intervention by the asthma educators. The asthma educators should now be able to identify from this data base those referrals that are not adopting best practice guidelines as assessed by the educators at initial contact and still decline an invitation to attend the service. It is a recommendation from this research that an attempt be made to contact this group and attempt to assess their reasons for declining the service by means of a simple questionnaire. For the purpose of service provision planning it would be more useful to receive feedback from this group of referrals.

8.4 Conclusion

This research project was recruited through personal invitation to eighty six families who had declined an offer to attend IAS self management education. The response rate was nine percent; in view of the target population this was considered by the researcher to be quite successful and adequate for the purpose of the study.

Each of the participants indicated at interview that they had declined the offer of self management education at the time of invitation by the educator. This confirms that intention to attend is a good indicator in this study population. It was an unexpected result to find that four of the respondents had previously attended self management education, this illustrates to the researcher that this group may be well motivated. The other two participants felt well resourced and had prior knowledge from other sources; that is work related experiences.

This research project and the literature has consistently identified the importance of well developed communication skills by the health professional; it is the key element in assessment of the severity of asthma, assessment of self management practices and implementation of behaviour change. Self confidence and perceived behavioural control were recurrent themes throughout the interviews with participants generally reporting high levels of self confidence in their ability to cope with and manage their children with asthma. Attitudes towards self management education were also found to have a strong correlation to this population's ability to adopt self management strategies, both in a positive and negative manner.

Within this study population this model, the Theory of Planned Behaviour has been applied to provide some insight into the participants' intention to attend self management education and to adopt self management strategies. However, the results also show that there are additional elements not captured within the framework of The Theory of Planned Behaviour.

9 REFERENCE LIST

Adams S, Pill R, Jones A, 1997, "Medication, Chronic Illness and Identity: The Perspective of People with Asthma," *Social Science and Medicine,* Vol 45, No 2, pp 189-201.

Ankey S, Metzgar E, Meyerson K, Shangle D, 2001, "Non-Compliance, Not Defiance: Understanding the Patient's Asthma Management Challenges," *AARC Times,* pp34-40.

Aroni R, Sawyer S, Abramson M, Stewart K, Thien F, Goeman D, Douglass J, 2003, "Asthma self management: What do we really mean?" *Australian Journal of Primary Health,* Vol 9, No's 2&3, pp10-17.

Australian Institute of Health and Welfare, Australian Centre for Asthma Management 2005, Asthma in Australia 2005 AIHW Asthma Series 2, Canberra.

Ajzen I, 1985, "From Intentions to Action: A Theory of Planned Behaviour" in Action control, from cognition to behaviour Edited Beckman J, Kuhl J, Springer-Verlag, Berlin.

Ajzen I, 1991, "The Theory of Planned Behaviour," *Organizational Behaviour and Human Decision Processes,* Vol 50, pp179-211.

Ajzen I, 2002, "Perceived Behavioural Control, Self –Efficacy, Locus of Control, and the Theory of Planned Behaviour," *Journal of Applied Social Psychology,* Vol 32, pp1-20.

Ajzen I, Fishbein M, 1980, Understanding Attitudes and Predicting Social Behaviour Prentice-Hall Inc, Engelwood Cliffs.

Ajzen I, Fishbein M, 2005, "The Influence of Attitudes on Behaviour," in The Handbook of Attitudes, Eds Albarracin D, Johnson B, Zanna M, Mahwah, Erlbaum.

Bauman A, Fardy H, Harris P, 2003, "Getting it right: why bother with patient-centre care?" *Medical Journal of Australia,* Vol 179, pp253-256.

Bauman A, Mitchell C, Henry R, Robertson C, Abramson M, Comino E, Hensley M, Leeder S, 1992, "Asthma morbidity in Australia: an epidemiological study," *The Medical Journal of Australia,* Vol 156, pp827-831.

Beyea S, Nicoll L, 1997, "Selecting samples for research studies requires knowledge of the populations of interest" *AORN Journal,* www.aorn.org/journal/research/rc1097. 20th Feb 2002.

Blessing Moore J, 1996, "Does asthma education change behaviour? To know is not to do" *Chest,* Vol. 109, (1) pp9-11.

Bodenheimer T, Lorig K, Holman H, Grumbach K, 2002, "Patient self management of chronic disease in primary care," *JAMA,* Vol 288, No 19, pp 2469-2475.

Brazil K, Krueger P, 2002, "Patterns of Family Adaptation to Childhood Asthma." *Journal of Pediatric Nursing,* Vol 17, No 3, pp167-173.

Brown R, 2001, "Behavioural Issues in Asthma Management" *Allergy and Asthma,* Vol 22, No 2, pp 67-69.

Buston K, Wood S, 2000, "Non –compliance amongst adolescents with asthma: listening to what they tell us about self management," *Family Practice,* Vol 17, No 2, pp 134-38.

Chapman K, Walker L, Cluley S, Fabbri L, 2000, "Improving patient compliance with asthma therapy" *Respiratory Medicine,* Vol 94, pp2-9.

Cochrane M, Bala M, Downs K, Mauskopf J, Ben-Joseph R, 2000, 'Inhaled Corticosteroids for Asthma Therapy, Patient Compliance, Devices and Inhalation Technique," *Chest,* Vol 117, No 2, pp 542-50.

Cooper A, Lloyd G, Weinman J, Jackson G, 1999, "Why patients do not attend cardiac rehabilitation: role of intentions and illness beliefs," *Heart,* Vol 82, No 2, pp234-6.

Coppa K, Boyle F, 2003, "The role of self help groups in chronic illness management: A qualitative study" *Australian Journal of Primary Health,* Vol9, No 2&3, p68-74.

Cote J, Cartier A, Malo J, Rouleau M, Boulet L, 1998, "Compliance with peak expiratory flow monitoring in home management of asthma" *Chest,* Vol 113, No 4, pp 968-972.

Crookes P, Davies S, 1998, Research into Practice, Bailliere Tindall, Toronto.

Dalheim Englund A, Rydstrom I, Norberg A, 2001, "Being the Parent of a Child with Asthma." *Pediatric Nursing,* Vol 27, No 4, pp 365-373.

Dinwiddie R, Mulier W, 2002, "Adolescent treatment compliance in asthma," *Journal of the Royal Society of Medicine,* Vol 96, pp68-71.

Eagar K, Hurst T, 2003, "Evaluation of the Illawarra Community Health Asthma Program" Centre for Health Service Development, University of Wollongong.

Fielding D, Duff A, 1999, "Compliance with treatment protocols: interventions for children with chronic illness," *Archives of Disease in Childhood,* Vol 80, pp196-200.

Fishwick D, D"Souza W, Beasley R, 1997, " The asthma self management system of care: What does it mean, how is it done, does it work, what models are available, what do patients want and who needs it?" *Patient Education and Counselling,* Vol 32, S21-33.

Foster M, Kendall E, Dickson P, Chaboyer W, Hunter B, Gee T, 2003, "Participation and chronic disease self management: Are we risking inequitable resource allocation?" *Australian Journal of Primary Health,* Vol 9, No 2&3, pp 132-140.

Franck L, Callery P, 2004, "Re-thinking family-centred care across the continuum of children's healthcare." *Child: Care, Health and Development,* Vol 30, No 3, pp265-277.

Gibson P, Coughlan J, Wilson A, Abramson M, Bauman A, Hensley M, Walters E, Self management education and regular practitioner review for adults with asthma (Cochrane Review). In *The Cochrane Library,* Issue 3, 2002. Oxford:Update Software.

Gibson P, Wilson A, 1996, "The use of continuous quality improvement methods to implement practise guidelines in asthma," *Journal of Quality Clinical Practice,* Vol 16 pp 87-102.

Glanz K, Lewis F, Rimer B, 1990, Health Behavior and Health Education Theory Research and Practice, Jossey-Bass Publishers, Oxford.

Goeman D, Aroni R, Stewart K, Sawyer S, Thien F, Abramson M, Douglas J, 2002, "Patients' views of the burden of asthma: a qualitative study" *Medical Journal of Australia,* Vol 177, pp 295-99.

Goeman D, Hogan C, Aroni R, Abramson M, Sawyer S, Stewart K, Sanci L, Douglas J, 2005, "Barriers to delivering asthma care: a qualitative study of general practitioners." *Medical Journal of Australia,* Vol 183, No 9, pp 457-60.

Grbich C, 1996, Health in Australia, Sociological Concepts and Issues, Prentice Hall, Sydney.

Griffin S, 1998, "Lost to follow up: the Problem of Defaulters from Diabetes Clinics" *Diabetic Medicine,* Vol 15, S14-S24.

Hall J, 1996,"Evaluating asthma patient inhaler technique" *Professional Nurse,* Vol 11, No11, pp725-29.

Hardeman W, Johnstone M, Johnstone D, Bonetti D, Wareham N, Kinmonth A, 2002, "Application of the theory of planned behaviour in behaviour change interventions: A systematic review" *Psychology and Health,* Vol 17, No 2, pp123-158.

Holman H, Lorig K, 2000, "Patients as partners in managing chronic disease" *British Medical Journal,* 320, 526-7.

Horner S, 1997, "Uncertainty in mothers' care for their ill children." *Journal of Advanced Nursing,* Vol26, pp 658-663.

Hull A, Alexander D, Morrison F, McKinnon J, 2002, "A waste of time: non-attendance at out-patient clinics in a Scottish NHS Trust," *Health Bulletin,* Vol 60, No 1, pp 62-68.

Huang N, 1997, Asthma Education Projects, "Education and Support for Chronic Illness Network, A Guide for Divisions Of General Practice." Public Health and Health Promotion SERU, Victoria.

Jarvis M, King A, Simpson P, Smith H, 1998, "Community Health Asthma Project Literature Review" Unpublished paper.

Jayasuriya P, Roach S, Bailey L, Shaw E, 2001, "Self management for chronic disease" *Australian Family Physician,* Vol 30, No 9, pp 913-916.

Jenkins C, 2000, "Diagnosis and clinical features of asthma in adults" in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Jenkins C, 2000, "Preventative Medications" in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Johnson G, Kent G, Leather J, 2005, "Strengthening the Parent Child Relationship: A Review of Family Interventions and Their Use in Medical Settings." *Child: Care Health & Development,* Vol 3, No 1, p 25-31.

Kieckhefer G, Ratcliffe M, 2000, "What Parents of Children with Asthma Tell Us." *Journal of Pediatric Health Care,* Vol 14, pp 122-126.

Kolbe J, 2002, "The Influence of Socioeconomic and Psychological Factors on Patient Adherence to Self management Strategies," *Manage Health Outcomes,* Vol 10, No 9, pp 551-570.

Kralik D, Koch T, Price K, Howard N, 2004, "Chronic illness self management: taking action to create order," *Journal of Clinical Nursing,* Vol 13, pp 259-267.

Kyngas H, Rissanen M, 2001, "Support as a crucial predictor of good compliance of adolescents with a chronic disease," *Journal of Clinical Nursing,* Vol 10, pp 767-774.

Lacy N, Paulman A, Reuter M, Lovejoy B, 2004, "Why We Don't Come: Patient Perceptions on No-Shows." *Annals of Family Medicine,* Vol 2, No 6. pp541-545.

Lo R, 1998, "A Holistic Approach in Facilitating Adherence in People with Diabetes," *The Australian Journal of Holistic Nursing,* Vol 5, No 1, pp 10-18.

Lorig K, 2003, "Self management Education, More than a nice extra," *Medical Care,* Vol 41, No 6, pp 699-701.

May T, 2002, Social Research Issues, methods and process Third Edition, Open University Press, Philadelphia.

Mahli P, 2001, "Psychosocial Issues in the Management and Treatment of Children and Adolescants with Asthma," *Indian Journal of Paediatrics,* Vol 68, pp S48-S52.

Mansour M, Lanphear B, DeWitt T, 2000, "Barriers to Asthma Care in Urban Children: Parent Perspectives," *Pediatrics,* Vol 106, No 3, pp 512-19.

Mason C, 1992, "Non-attendance at out-patient clinics: a case study," *Journal of Advanced Nursing,* Vol 17, pp 554-60.

McCarthy M, Hanson J, Herbert R, Wong D, Brimacombe M, Zelman M, 2002, "Empowering Parents Through Asthma Education, *Paediatric Nurse,* Vol 28, No 5, pp 465-473.

McKenzie J, Smeltzer J, 2001, Planning, Implementing and Evaluating Health Promotion Programs, 3rd Ed, Allyn and Bacon, Singapore.

McQuaid E, Walders N, Borrelli B, 2003, "Environmental Tobacco Smoke Exposure in Pediatric Asthma: Overview and Recommendations for Practice." *Clinical Pediatrics,* Vol 42, No 9, pp 775-87.

Milnes L, Callery P, 2003, "The adaptation of written asthma self management plans for children with asthma," *Journal of Advanced Nursing,* Vol 41, No 5, pp 444-453.

Minichiello V, Aroni R, Timewell E, Alexander L, 1996, In-Depth Interviewing, Principles, Techniques, Analysis, 2nd Ed, Longman, Melbourne.

National Asthma Council Australia, 2002, Asthma Management Handbook, National Asthma Council Australia Ltd.

NSW Health Department, 2000, NSW Health Frontline Procedures for the Protection of Children and Young People

Osman L, 1996, "Guided self management and patient education in asthma" *British Journal of Nursing,* Vol 5, No13, pp 785-89.

Paterson B, Russell C, Thorne S, 2001, "Critical analysis of every-day self-care decision making in chronic illness," *Journal of Advanced Nursing,* Vol 35, No 3, pp335-341.

Peat J, 2000, "Epidemiology and the changing prevalence of asthma" in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Phelan P, 2000, "The natural history of asthma from childhood into adult life," in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Polgar S, Thomas S, 1991, Introduction to Research in the Health Sciences, Churchill Livingstone, Melbourne.

Put C, Van den Bergh O, Demdts M, Verleden G, 2000, "A Study of the Relationship Among Self-Reported Noncompliance, Symptomatology, and Psychological Variables in Patients with Asthma" *Journal of Asthma,* Vol 37, No 6, pp 503-510.

Putman W, Burge F, Tatemichi S, Twohig P, 2001, "Asthma in Primary Care: Making guidelines work," *Canadian Respiratory Journal,* Vol 8, SuppA, pp 29A-34A.

Richards L, 1999, Using NVivo in Qualitative research, Victoria, Australia: Qualitative Solutions and Research Pty. Ltd.

Rubinfeld A, 2000, "Asthma management – putting it all together" in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Sawyer S, 2002, "Action plans, self-monitoring and adherence: changing behaviour to promote better self management," *Medical Journal of Australia,* Vol 177, pp S72-4.

Sawyer S, Aroni R, 2003, "Sticky issue of adherence" *Journal of Paediatric and Child Health,* Vol 39, pp2-5.

Sawyer S, Zalan A, Bond L, 2002, "Telephone reminders improve adolescent clinic attendance: A randomised controlled trial," *Journal of Paediatric and Child Health,* Vol 38, pp78-83.

Shinitzky H, Kub J, 2001, "The Art of Motivating Behaviour Change: The use of Motivational Interviewing to Promote Health." *Public Health Nursing,* Vol 18, No 3, pp 178-185.

Sidebotham P, 2001, "Culture, Stress and the Parent Child Relationship: A Qualitative Study of Parents' Perceptions of Parenting." *Child:Care Health & Development,* Vol 27, No 6, pp 469- 480.

Spector S, 2000, "Review article, Noncompliance with Asthma Therapy – Are There Solutions?" *Journal of Asthma,* Vol 37, No 5, pp 381-388.

Stott N, Rees M, Rollnick S, Pill R, Hackett P, 1996, "Professional responses to innovation in clinical method: diabetes care and negotiating skills," *Patient Education and Counselling,* Vol 29, pp 67-73.

Tettersell J, 1993, "Asthma patients' knowledge in relation to drug therapy," *Journal of Advanced Nursing,* Vol 18, pp 103-113.

Thomson N, 2001, "Triggers of asthma" in Manual of Asthma Management Edited O'Byrne Paul M, Thomson Neil C, WB Saunders, Toronto.

Toelle B, Ram F, 2002, "Written individualised management plans for asthma in children and adults (Cochrane Review)." *The Cochrane Library,* Issue 3,. Oxford Update Software.

Trollvik A, Severinsson E, 2004, " Parents' experiences of asthma: Process from chaos to coping." *Nursing and Health Sciences,* Vol 6. pp 93-99.

Turner J, 2005, "A Place for Attachment Theory in Child Life Programming: The Potential to Assess the Quality of Parent - Child Relationships." *Child & Youth Care Forum,* Vol 34, No 3, pp195-207.

Van Asperen P, Mellis C, 1994, Triggers – avoidable or not? *The chesty child.* pp 47-63.

Vermeire E, Hearnshaw H, Van Royen P, Denekens J, 2001, "Patient adherence to treatment: three decades of research. A comprehensive review." *Journal of Clinical Pharmacy and Therapeutics,* Vol 26, No 5, pp 331-42.

Walls R, 2000, "Control of allergic disease and immunotherapy in asthma," in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Walters A, Walters E, 2000, "Oral corticosteroids and immunosuppressives" in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Weeks A, McAvoy B, Peterson C, Furler J, Walker C, Swerissan H, Belfrage J, 2003, "Negotiating ownership of chronic illness: An appropriate role for health professionals in chronic illness self management programs" *Australian Journal of Primary Health,* Vol 9, No 2&3, pp 25-33.

Weinstein A, 2000, "Asthma Treatment and Noncompliance" *Delaware Medical Journal,* Vol 72, No 5, pp 209-213.

Woolcock A, 2000, "Definition and classification of asthma," in Understanding Asthma A Management Companion Edited Walls Ronald S, Jenkins Christine R, Maclennan & Petty, London.

Woolcock A, Bastiampillai S, Marks G, Keena V, 2001, The Burden of Asthma in Australia, Commonwealth Department of Health and Aging.

Worstell M, 2000, "Asthma: individual patient perspective and current unmet needs," *Clinical and Experimental Allergy,* Vol 30, Supp 1, pp 11-15.

Yoon R, McKenzie D, Miles D, Bauman A, 1991, "Characteristics of attenders and non-attenders at an asthma education programme," *Thorax,* Vol 46, pp 896-890.

www.who.int/respiratory/asthma/definition

www.ohprs.ca/hp101/print/module4

www.phenomenologycentre.org/phenom.htm

10 APPENDICES

10.1 Appendix One: Information Sheet

INFORMATION SHEET

A qualitative study which explores the reasons for non attendance at the Community Health self management education program for the carers of children with asthma.

Research student : Heather Smith, Phone No. 4221 4209

Supervisors : Sandra Jones and Joanne Joyce

Department of Nursing, The University of Wollongong, Phone No. 4221 4209

Your child has been referred to the Community Health Asthma Program in the past year or so. One of the Community Asthma Educators would have approached you either by telephone or letter and invited you to attend an asthma clinic. At the time this may not have suited your needs and you chose not to attend.

A research project is currently being undertaken by a masters of nursing student, Heather Smith, from the University of Wollongong; the aim of this research is to determine people's rationale behind that choice. The researcher would like an opportunity to discuss this with you. It is anticipated that interviews will take up to an hour to complete. A mutually convenient time and place will be negotiated with you if you choose to participate.

Interviews will be recorded on an audio-tape and later transcribed. Initially your name and contact details will be maintained and coded with your interview so points may be clarified and meanings checked as necessary. At the time of writing the information up it will be de-identified and presented anonymously.

Confidentiality will be maintained at all times with transcripts kept locked at The University of Wollongong.

Participation in this research is voluntary; you may change your mind at any time and withdraw your consent and also withdraw your data. Your participation or refusal to participate will not affect in any way your relationship with Illawarra Health and will not affect service provision from the Community Asthma Educators now or in the future.

It is hoped that this research will provide some insight into the needs of people with asthma and their families who at the moment are not using available services. The results will help the asthma educators to better target the service to you.

Results and findings will be presented to the UOW, and may be shared with colleagues and professional peers or published. A summary of the findings will be made available for the participants.

Any concerns or complaints about how the research is or has been conducted should be directed to the Secretary of the University of Wollongong Human Research Ethics Committee on 4221 4457.

10.2 Appendix Two: Consent Form

UNIVERSITY OF WOLLONGONG
CONSENT FORM

A qualitative study which explores the reasons for non attendance at the Community Health self management education program for the carers of children with asthma.

I have been given an information sheet about a qualitative study which explores the reasons for non attendance at the Community Health self management education program for people with asthma and their carers.

I have had an opportunity to ask Heather Smith any questions I may have about the research and my participation.

I understand that my participation in this research is voluntary; I am free to refuse to participate, and I am free to withdraw from the research at any time or to withdraw my data.

By signing below I am indicating my consent to participate in the research entitled A qualitative study which explores the reasons for non attendance at the Community Health self management education program for the carers of children with asthma conducted by Heather Smith as it has been described to me in the information sheet and in discussion with Heather Smith. I understand that the data collected from my participation will be used for thesis and possibly journal publication and I consent for it to be used in that manner.

Signed Date

..../...../.....
Name (please print)