The Development of Self-Regulation in Mothers of Children with Asthma: A Qualitative and Quantitative Study

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Finally, I dedicate this thesis to my mother, Patricia Madge 1932-1983

"*We all indulge in this strange, pleasant process called thinking, but when it comes to saying, even to someone opposite, what we think, then how little we are able to convey*" - Virginia Woolf.

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SUMMARY

Asthma is the commonest chronic disease of childhood. It is also the most frequent cause of hospital admission, with rates of admissions being highest in children under five years of age. Asthma is an episodic disease that changes over time and has several different presentations in children. Diagnosis is not straightforward, and may be delayed in the very young. Treatment of asthma in the under fives is particularly problematic, with difficulties around both the administration and efficacy of drug therapy.

Parents of young children with asthma require support to develop the necessary strategies and skills to best control the disease and allow them to take a primary role in managing their child's disease. Educational programmes to develop skills in parents of young children have had limited success. This may be because current interventions are neither based on appropriate behavioural theories, nor are sympathetic to the beliefs of parents. Self-regulation is emerging as an important theory for understanding behavioural approaches to asthma. However, most studies of asthma self-regulation have focused on adults and parents of older children and little is known about how or when self-regulation develops in carers of young children with asthma.

The present qualitative study explored the circumstances around the onset and diagnosis of asthma in young children, the development of self-regulation in their mothers and the impact of their mothers' beliefs on the development of self-regulation. Qualitative interviews were conducted with twenty-one mothers of young children with asthma. The mothers had all attended a large Children's Teaching Hospital in the West of Scotland with their children. The principles of grounded theory were used to direct qualitative data collection and analysis. To compliment findings from the qualitative interview a questionnaire assessment of illness perception and psychological predictors of disease management behaviours was included.

Four key themes emerged from the qualitative analysis; Vigilance, the Void, Connection and Lay Models of Asthma.

(i) Vigilance: The mothers were highly vigilant, and promptly spotted the onset of asthma in the child. At this stage, the mothers had often sought medical help and advice but had found it unhelpful. The mothers observed patterns of illness developing in their children. In time, these were assembled into personal models, which often led them to make a lay diagnosis of asthma.

(ii) The Void: Despite the presence of important diagnostic cues the mothers experienced a delay in receiving a diagnosis of asthma for their children. In contrast the mothers reported a consistently high awareness of the diagnostic symptoms they were seeing. They had often arrived at a diagnosis of asthma based on their lay interpretations of the signs and symptoms. For the mothers this period was associated with feelings of uncertainty and helplessness.

(iii) Connection: As the asthma developed the mothers reached an important turning point where they recognised a 'connection' between specific actions and outcomes in relation to their child's asthma. While most reached connection over a period of time and reflection, in others it seemed to come as a flash. Having made the connection the mothers proceeded to engage in strategies to regulate their child's asthma. Key factors of influence toward connection were having a belief that asthma was serious, recognising the importance of giving preventive medication, taking full responsibility for the child's asthma and increased self-confidence in one's ability to influence the course of disease events.

(iv) Lay Models of Asthma: The mothers had all developed personal models of asthma. The models they held were generally convergent with current biomedical understanding of asthma. There was no evidence that the mothers' beliefs had interfered negatively with their development of self-regulation. All of the mothers believed the asthma would remit or improve with time suggesting that beliefs that the asthma was serious was more influential than beliefs about asthma being a permanent illness.

The results of the psychological questionnaires, analysed independently from the interview data, showed that the mothers were within accepted norms for measures of coping, illness perception, personality and conscientiousness.

The study described the experiences of a group of mothers confronting asthma developing in their child and how they reached a stage where they were able to regulate their child's asthma by engaging in observational activity, making judgements about intervening with appropriate management strategies, and assessing whether their intervention was successful. Connection (making the link between strategy and outcome) is a key component underpinning self-regulation. It describes an important gateway between an individual who uses management practices versus an individual who derives successful strategies to regulate a child's asthma. Collectively the findings mark an important expansion in current understanding of the development of self-regulation in mothers of young children with asthma.

CHAPTER 1. INTRODUCTION

Starting Perspective

My professional background is Nursing hence I approached this thesis from the practical perspective of being faced in daily practice with mothers caring for young children with asthma but recognising that I did not have a reliably effective package of care to offer them.

Whilst I had previous experience in health service research there were many new disciplines to explore and make sense of in order to complete competently this research. The main body of the research adopted a qualitative approach.

In the literature the term self-regulation is used both in relation to an individual regulating his/her self and to a parent regulating a disease on behalf of his/her child. In this thesis the researcher used the term 'self-regulation' because it was considered to most accurately describe the parents' experience. That is because the children studied were less than five years of age it was assumed that the parents were acting completely on behalf of the young child thus it was their behaviour that was being directed by the 'self'. Consideration was given to their 'by-proxy' situation at further intervals throughout the thesis, and is highlighted at the time. For example in Chapter 7, Lay Models of Asthma and in Chapter 8, Triangulation.

Literature Review Methods

There was no single literature search for the study, rather the literature continued to inform the study as it progressed. An initial literature review focused on the key terms asthma and self-regulation in the English language. The databases of MEDLINE, EMBASE, CINAHL, and PSYCHinfo were used. These were expected to capture literature from across a range of disciplines including general medical science, psychology and social sciences. Additionally, the researcher visited the specialist library at the University of Glasgow's Department of Clinical Psychology, for access to specific reference books. Initially the literature was reviewed back to 1960. It was assumed that historical origins of some elements of the background might be important and informative. As the study progressed, it

was possible to limit further searches to within a shorter, and more recent, time-scale.

To keep up to date with the literature throughout the period of study the following four procedures were employed.

1. Regular electronic searches using the Current Awareness Auto-alert Service were set up through the University of Glasgow main campus library. For this the search terms included: Asthma OR wheez* AND education* OR self-management OR self-regulation.
2. The Zetoc Auto-alert service was set up in order for the researcher to be emailed table of contents of key journals relevant to the thesis, as they were released. These included key respiratory journals - Thorax, Journal of Clinical Allergy and Immunology, Journal of Asthma, and Respiratory Medicine; key medical journals - BMJ and Lancet, as well as journals relating to patient education - Patient Education and Counselling and Health Psychology.
3. At two to three monthly intervals the researcher conducted searches through the NHS e-library on 'Self Regulation' and a number of key authors.
4. Articles were also obtained from hand searched bibliographic lists from key publications.

Asthma

This thesis is focused on maternal management of asthma in young children under 5 years of age. The following section sets out briefly current understanding of the disease in relation to young children.

The burden of illness

Respiratory illnesses are the most commonly reported chronic childhood illnesses in the UK, of which 80% are due to doctor-diagnosed asthma[1]. Time trends show the prevalence of childhood asthma and wheeze has risen substantially during the past three decades, although more recent estimates suggest some levelling off[2-6]. Estimated prevalence for current asthma in UK children ranges from 12.5% to 15.5%[1], almost double that for adults[7]. There is also evidence of variation with

age, with the biggest increases in current wheezing seen in pre-school children, with a rise from 12% in 1990 to 26% in 1998[4]. As the numbers of pre-school children with asthma have increased, they have come to place a significant burden on health care resources.

The impact of childhood asthma on health service use is high, with diagnosed asthma accounting for 5% of primary care consultations in children[8], and 14% of hospital admissions for respiratory disease[9]. Within hospital asthma admission data, rates are highest for the 0-4 year old group, and proportionally more common in boys[9], making the costs bigger for this age group than any other[10;11]. Children with multiple admissions tend to have the index (first) admission earlier in life[12] and being under 5 years of age is a risk factor for readmission/s[13]. The risk of an asthma attack in children rises with disease severity highlighting the importance of the effective management of persistent symptoms[14].

Diagnosis of asthma

Asthma has been defined as "*a chronic inflammatory disorder of the airways ... in susceptible individuals, inflammatory symptoms are usually associated with widespread but variable airflow obstruction and an increase in airway response to a variety of stimuli. Obstruction is often reversible, either spontaneously or with treatment*"[15].

Despite the emphasis on inflammation in the above definition, the diagnosis of asthma at all ages remains a clinical one with no specific diagnostic test. Diagnosis is based largely on the occurrence of symptoms, most commonly breathing difficulties associated with cough and wheezing that frequently limit activity and/or disturb sleep. In the pre-school child, diagnosis is additionally hampered by the lack of clinically available objective diagnostic tools such as lung function measurements. Even when there are clear diagnostic pointers in a particular child, clinicians vary in their threshold to making a diagnosis of asthma and prescribing treatment[16;17].

For many parents of a pre-school child the time before the diagnosis is reached is fraught with uncertainty and anxiety because of diagnostic delay in reaching a

diagnosis of asthma. Not surprisingly, these parents report often feeling unsupported by their health professionals[18].

Over time asthma generally follows a remitting and relapsing course with associated variations in severity. In children, the pattern of disease varies widely. Long term follow up studies of the very young have revealed distinctive patterns of wheeze/asthma with different patterns of progression: some children have occasional wheezing (*Transient wheezers*) in response to respiratory tract infections; others have persistent daily symptoms (*Persistent asthma*) of chronic airway obstruction, triggered by a wide variety of factors[19;20]. These patterns have different long-term outcomes. While transient early wheezers show a pattern of repeated and sometimes severe symptoms with viral infection, their symptoms often resolve completely by about 6 years of age. For those with more persistent asthma, the long-term prognosis may be associated with symptoms that persist into adult life. Lung function deterioration may occur although the evidence suggests this often occurs in the course of the disease and then remains stable[19;20].

Management of asthma in general

At present, there is no cure for asthma. The main thrust of treatment is directed to controlling the disease usually through the use of pharmacological treatment[21]. The aim of drug treatment is to achieve the control of symptoms with no, or minimal, side effects[21]. As understanding of the underlying mechanisms involved in the inflammatory processes has grown, prescribing has come to focus on treatment to suppress airway inflammation, primarily using inhaled corticosteroids, commonly referred to as '*preventers*'[22], supplemented with treatment to relax bronchial smooth muscle, beta2 agonists, commonly referred to as '*relievers*'. With the advent of more effective drug therapy for asthma and the development of better drug delivery systems, most children's asthma symptoms can now be controlled, if their drug regimes are adhered to. Inhaled therapies are preferred because of the range of drugs available and because inhalation allows the delivery of small amounts of medicines to the key target organ leading to rapid drug actions with minimal side-effects[21;23;24].

Management of the pre-school age child with asthma

Unfortunately, there are problems specific to young children that make the pharmacological treatment of asthma and acute wheezing episodes particularly challenging. The three main problems are; practical difficulties relating to inhaled medicine administration; uncertainty regarding the significance and interpretation of acute asthma-like symptoms in young children; and limited efficacy of current drug treatments.

(i) Practical difficulties

On a practical level delivery of inhaled treatment is difficult with few 'toddler-specific' inhaler devices. Most asthma inhaler devices require that the patient can comply with instructions on how to breathe and hold breath[25;26]. Cooperation of the child has been shown to be an essential determinant of adequate dose delivery[27]. However, cooperation can be extremely difficult to achieve in practice. This may contribute to poor parental adherence to prescribed drug regimes through reluctance to manage a struggling child[28;29].

(ii) Uncertainty regarding the cause and significance of acute asthma-like presentation

Intermittent episodes of acute wheezing caused by viral respiratory infections represent a common experience for the parents of young children. Repeated viral respiratory infections in the young are extremely common and for the busy clinician/GP it can be extremely difficult to distinguish occasional colds from an intermittent pattern of symptoms more in keeping with asthma[30]. Maintenance treatment should be given to those with chronic inflammation. However, without better methods to distinguish the different phenotypes in children presenting with recurrent wheezing it remains difficult to target those most likely to benefit from therapy.

(iii) Limited efficacy of asthma drugs in the young.

Even when there is clarity around the asthma phenotype, uncertainty regarding the use of standard asthma pharmacology in the very young persists[31-33]. Whilst there is some evidence that maintenance inhaled corticosteroids decrease asthma exacerbations in preschool children with persistent asthma[32] the effects

for viral induced wheeze are less clear[34]. One study of pre-school age children treated for a four month period showed no benefit over the control group in number or duration of wheezing episodes[35]. Further ambiguity surrounds the use of emergency short courses of oral steroids (a common treatment approach for an acute exacerbation) in the preschool group, with studies showing both a positive[36-39] and negative effect[40;41].

Such discrepancies compared with response to treatment in adults point to differences in the underlying patho-physiology of the disease in the very young, and highlight the difficulties clinicians face on pharmacological decision-making. These difficulties often result in parents appearing to be left in 'limbo' managing a child who is suffering repeated frequent asthma-type episodes for whom treatment decisions are avoided or may be conflicting, factors known to be associated with poor treatment adherence[42-44].

Summary

Given the complexities of diagnosis and treatment of asthma in the young child, practical management represents a significant challenge for clinicians and families. The next section reviews the evidence around the efficacy of patient education intervention studies designed to support parents of young children with asthma.

Intervention studies targeting parents of pre-school age children with asthma

The key management tasks that parents have to learn

Given the difficulties around diagnosis and treatment it is not surprising that health professionals have looked to alternative strategies and interventions to supplement care of asthma in the pre-school child. One approach has been the provision of 'patient education', now strongly recommended in asthma guidelines[21]. In general, patient education has been associated with a range of improved health outcomes[21;45;46]. In contrast, in pre-school children, the evidence base is weak[47].

Most patient education programs focus on the development of the patient's 'self-management' skills, supported by enhanced asthma care provided by the health professional, for example, a structured clinic review or the provision of an asthma action plan. There is however an ongoing debate regarding the definitive, successful, content of asthma education programmes, and it is clear there is no 'one fit for all'. Traditionally, content has been influenced by research findings and expert opinion[48;49]. Both have problems. Application of findings from research studies is frequently difficult as the exact setting of a study can rarely be replicated because of differences of ages and cultures and expert opinion does not necessarily capture what is needed by patients.

Studies from the 1980's provided a useful framework to begin to define the types of tasks that families might undertake in order to control the disease and minimise disruption in daily life[49-51;51]. In a critical incident study Wilson et al examined 1,300 reports of family and child (aged 9-13 years) responses to an asthma episode[51]. From the data, 66 specific self-management behaviours associated with a favourable outcome were identified. These were condensed into 21 self-management competencies of four types: Prevention, Intervention, Compensatory behaviours and External controlling factors. *Prevention* covered any behaviour that helped to avoid an asthma episode or prevent occurrence of symptoms, e.g. avoiding or minimising exposure to allergens and triggers, taking preventive medication. *Intervention* behaviours covered actions taken after the attack had begun, e.g. removing oneself from the source of trigger, remaining calm during the attack, and taking medication. *Compensatory behaviours* were classified as demonstrating the child's adjustment and coping with the situation. These included cooperating with medical regimes, not denying the condition or blaming one's self, dealing with peers and accepting responsibility for managing one's own condition. *External controlling factors* covered actions taken by adults that interfered with the child's ability to manage the situation. For example, in school/nursery the main factors were authority figures who, deny the condition and fail to provide help, and family problems that precipitate attacks. The authors went on to use the critical competencies as learning objectives in a paediatric asthma education program. Whilst the numbers in the study were very small (N=14 in total) there was an improvement in favour of the programme.

Using a similar technique, Wilson et al assessed 574 detailed descriptions of effective and ineffective asthma management behaviours of parents of young children with asthma (aged under 7 years) to further identify key areas of responsibility[52]. The descriptions were collected from health professionals (N=117) and parents (N=112). Five general areas of parental responsibility were extracted: symptom intervention, symptom prevention, use of medical and educational resources, communication among caregivers and child development and family relationships. Vital information on ineffective behaviours highlighted how 'at odds' the parents actual behaviour was and areas where future interventions might focus. Failure to act appropriately was noted in terms of symptom recognition, medication use and communications.

Such studies demonstrate that parents must at the very least develop skills to monitor the child's asthma, avoid triggering situations, and successfully administer anti-asthma medication. The situation is made more complex as parents are acting on their child's behalf often with little direct verbal information or feedback to go on. The situation may be compounded by the absence of a prompt accurate diagnosis and effective treatment[53;54]. In reality this creates a very weak framework with which families must operate and develop skills.

Review of patient education programmes for parents of pre-school children with asthma

A close examination of the literature identifying the characteristics and findings of the limited number of studies focusing exclusively on the pre-school child studies should provide a useful starting point for hypothesising about defining a 'successful approach for the future', and identifying areas of uncertainty, which require further investigation. Six studies addressing preschool children were identified.

Study 1 – 1985

Whitman's study of a self-care rehabilitation program for paediatric asthma was conducted in the USA in the 1980's and is the earliest report of a dedicated asthma education program for the pre-school age group[55]. The study had two parts. The first targeted children 6-14 years of age, the second a small group (N=21) of 2-5 year olds and their parents. Two asthma programs were developed

for each age group, and each was treated and analysed separately. Whilst the older group were randomised to either; treatment and control, the pre-school group (the one of interest here) acted as its own control with pre and post training comparisons. The aims of the programs were to inform children and parents about asthma in a way to assist their practical management at home and to help cope with the emotional impact of asthma. The pre-school program consisted of six, one-hour classes scheduled twice a week for 3 weeks, and was delivered to child and parent together. The clinical outcomes assessed were number of asthma episodes (recorded in parent held diary records of asthma episodes occurring during the study), and severity of asthma episodes. These were measured for three-months pre-training (essentially the control data), and three-months post training. Following training, asthma episodes had halved ($p=0.01$, from 10.1 to 5.14), and number of severe asthma days had reduced ($p=0.04$). There was no observed difference for number of mild or moderate asthma days. This suggested that within the group there were some children with persistent asthma who were the ones who responded. Despite the very small numbers studied and the lack of control group, the study did suggest that there was a benefit from delivering a structured asthma program to pre-school children with persistent asthma and their families.

Study 2 – 1994

Mesters et al performed an early randomised controlled trial of an asthma education programme in the Dutch primary care setting in young children with asthma[56]. The study assessed the impact of a multi-disciplinary modular education programme for general practitioners on parental knowledge, attitudes, self-efficacy, self-management behaviours and state anxiety over a six-month period. The programme content was directed by a previous needs assessment of target parents and a task analysis of primary care providers. The resulting educational programme consisted of a manual including 16 modules, which the general practitioner was to use during asthma contacts with the study families. A simplified version was also given to the parents. The manual topics included recognising common asthma symptoms, problem solving with medication, and recognising early asthma attacks. It was at the general practitioners' discretion which module was used and in which order during contact with the parent. Sixty-seven general practitioners were recruited and randomised to either treatment

group (TG, N=35) or control (CG, N=32). There were no significant differences in the kind of parents and children recruited by the two doctor groups. In general, the parents were largely mothers (TG 98%, CG 97%), the children were less than three years of age (TG mean age 2.5 years, CG mean age 2.3 years), with mild to moderate asthma severity. At the end of the study period, the majority of doctors (91%) reported that they had managed to discuss all, or nearly all, of the content in the manual with the families they had seen. On average five contacts at three-weekly intervals were needed to discuss all of the information. There were significant differences in parental asthma knowledge (p=0.01), in the level of self-efficacy expectations (p=0.02), in the frequency of performing self-management behaviours (p=0.01) and in the attitude to asthma (p=0.01) in favour of the general practitioner treatment group (TG). The level of state anxiety was unaffected (p=0.74). The authors suggest that the observed gain in performing self-management behaviours occurred directly as a result of the increase in knowledge and perceived self-efficacy. Whether the positive change in behaviour was maintained in the long term is not known. The decision to target the intervention at general practitioners was unusual for the time and has not until recently been replicated[57].

Study 3 - 1996

Wilson et al studied a group of parents of young children with recurrent wheezing and diagnosed asthma aged 1-6 years of age in the USA[58]. The program aimed at improving the necessary knowledge, skills and motivation required for families to prevent asthma symptoms successfully, to manage symptoms when they occurred, and to utilise medical services appropriately. The intervention consisted of small-group sessions, each of two hours duration, conducted at weekly intervals by an experienced paediatric asthma nurse. It included behaviour change strategies based on social learning theory, with activities structured to ensure successful mastery as well as enhancing sense of self-efficacy. The impact of the program was assessed over a three-month period on a number of clinical (symptom free days, parental sleep interruption, reduction in symptoms, reduction in number of asthma-sick days) and behavioural outcomes (number of times parent practiced symptom management and prevention, frequency of beginning asthma medication promptly and parental 'feelings' scale). Parents were eligible for inclusion in the study if they had a young child between the ages

of six months and six years, with a history of diagnosed asthma or recurrent wheezing and recent contact with acute services, that is they were a clinically active group. Out of 129 eligible families, 76 agreed to take part. Parents were stratified according to their child's age (0-3 or 4-6 years) and randomised to either education group (EG, N=41) or control group (CG, N=35). At the end of the study significant differences in favour of the EG were observed on two of four of the clinical outcomes vis. number of symptom free days ($p<0.02$) and parental sleep interruption ($p<0.001$). In terms of impact on the behavioural outcomes, there was again a significant improvement in favour of the EG for preventive medication adherence ($p=0.01$) and early intervention ($p=0.05$). The study showed that at least in the short term small-group parental training for asthma was effective. Whilst the results are based on parental records, and therefore subject to recall bias, the attendance at sessions was extremely high (95% parents attended all sessions) suggesting that it was well received by the target audience and that they engaged with the content. The EG also received a personalised asthma plan developed during the program, a factor known to be important for management of older children and adults[21].

Study 4 - 1998

An unusual approach was adopted in Australia by Holzheimer et al[59] who chose to target the children themselves, despite their young age. The group worked on the premise that young children had a greater capacity to understand the nature of illness than acknowledged and as they are most likely to experience asthma symptoms early in their life engaging them in positive asthma management processes at an early age might prove to be important in their longer-term health. Two mediums for learning were developed: a video and picture book. The content of both was informed by expert knowledge and based on appropriate childhood asthma management competencies[51]. It included both theoretical topics e.g. information on asthma triggers and behavioural strategies such as engagement in relaxing activities when receiving asthma medication administered by a parent. In both the educational messages were presented in an engaging manner, and were supplemented by modelling techniques using specially trained child-actors. The video was extremely short (4 minutes long) and the picture book used visual images with minimal text. No information on the reading time required to complete the book is given. Eighty children, aged 2 to 5

years old, (mean age 4 years), all of whom had doctor-diagnosed asthma (mean asthma duration 2.5 years), and were receiving daily asthma medication were recruited into the study. The outcomes were knowledge (assessed using an eight question pictorial multi-choice questionnaire), compliance with medication and health status defined as days of wheeze and cough and contact with medical services for asthma. Both compliance and health status were assessed using parent-completed diary records. The children were randomly allocated to one of three experimental groups or to a control group (n=20). Experimental group 1 received the video and book (n=20) group two the video and unrelated book (n=20), group three the book and unrelated video (n=20). The control group saw and read an unrelated video and book. The interventions were delivered on an individual basis to the child and parent on three occasions over a four-month period. Knowledge was assessed immediately before and after each delivery in intervention. During the four months, parents were asked to complete daily diary cards at home. Assessments were performed at the start and following each intervention visit (four occasions in total). At baseline, there was no significant difference in knowledge between groups, and all four groups showed an improvement at the end of the monitoring period. However, within groups there were differences in the magnitude and speed of improvement. Group 1 (video and book) showed both the highest increase in knowledge overall, and the largest incremental improvements over time, suggesting that the combination of mediums create a more potent intervention. As in other studies, completion of the parent held diary cards was of variable quality and often incomplete (only 90% presented a diary card at end of study)[60]. Despite participating in a research study, 24 of the parents admitted to stopping their child's asthma preventive therapy completely (these parents were from all 4 groups), and thus the data reported is incomplete. Not unsurprisingly all four groups of parents reported non-compliant days. Whilst children in the experimental groups experienced on average less non-compliant days, and less days with wheeze and cough the only significant difference found was between group 1 and 4 with regard to number of medical consultations for asthma. In general, the study failed to make an impact on compliance or health status. This may in part be due to a very short monitoring period and relatively small numbers in the respective groups.

Study 5 - 2002

Stevens et al reported the impact of a parental education programme, which included a written guided self-management plan for parents of pre-school children in the UK, evaluated in a randomised controlled trial format[47]. The intervention, developed from two previously successful UK studies in older children[61;62] included the provision to parents of a pre-school asthma book and a written guided asthma plan, supplemented by two 20-minute structured educational sessions given by a specialist asthma nurse. Sessions, all conducted on an individual basis, were given one month apart. Parents were eligible for the study if their child had had a recent attendance at hospital (either a full admission or Accident & Emergency visit) for severe asthma or wheeze and were aged between 18 months and five years. 200 children aged 18 months to 5 years were identified, and parents were randomised to either intervention group (IG, N=99) or control group (CG, N=101). The primary outcomes were general practice consultations, hospital readmissions and attendances at Accident & Emergency, while the secondary outcomes were disability score, parents' quality of life, and parental knowledge of asthma. Subjects were assessed at 3, 6 and 12 months. At the end of the study, there was no significant difference observed between the groups on any of the primary or secondary outcomes. It is not clear why there was no effect seen on any measure. Follow-up data was available for 89% of the sample and the intervention was implemented close to the time of an acute admission, a factor thought to be important for overall effect. It is worth noting that unlike some other studies of this type the intervention was not designed on information derived from the target group regarding their perceived educational and emotional needs.

Study 6 - 2003

The final study was a controlled clinical trial of a cognitive-behavioural programme. Warschburger et al assessed the impact on short and medium term follow-up (six months later) of two different types of parental asthma education on knowledge, self-efficacy, and quality of life delivered prior to discharge from an inpatient rehabilitation centre[63]. One parent, identified as the person with the primary responsibility for the asthmatic child, (aged 8 years or under) was randomised to either instruction centred group (ICG, N=100, information only) or behaviour centred program (BCP, N=85, information plus cognitive behavioural techniques). The interventions for both groups were delivered using small group

training techniques. The ICG received two-90 minute information sessions covering typical asthma topics as recommended in most consensus guidelines[21]; basic asthma physiology, symptom recognition, trigger avoidance, asthma medication action, and attack management procedures. The teaching methods employed focused on modelling and persuasive communication. The BCP comprised of six-90 minute sessions, the first two units being identical to the ICG. The four additional sessions covered perception of early warning signs, medication delivery techniques, non-pharmacological techniques for handling asthma symptoms, stress management techniques, and cognitive behavioural therapy techniques for handling critical situations and relapse. Parents were encouraged to share within the class their own unique problems and discuss training content and application to their own personal situation. The sessions were largely interactive and included practical assignments to complete at home. Both groups received a personalised written asthma action plan prior to discharge. The primary outcomes were asthma severity (Asthma Functional Severity Scale) Quality of Life (Paediatric Asthma Caregivers Quality of Life Questionnaire), Knowledge (Knowledge questionnaire) and self-efficacy (using asthma specific self-efficacy questionnaire). All four outcomes were assessed at baseline, at discharge immediately following the intervention (except knowledge), and six months later.

All the outcomes improved significantly within both groups, but there was no difference between groups. Both groups received the information in a format, which appears to have been well received by the parents. Both groups received a written asthma action plan, a factor shown to be important in improving outcome following discharge for both older children and adults[21]. One of the main problems with this study appears to be lack of an adequate control group making it unclear which component of the intervention/s was responsible for the improvement.

Conclusions drawn from review of pre-school specific programmes

One of the main problems when trying to draw conclusions from a review of these six studies is the small number of subjects and the differing methodology employed, a problem highlighted in systematic reviews of patient education studies[46;64]. There has been no single approach, which has consistently shown

improvement. Methodologically, the studies were fairly sound, although many were based on small subject numbers. They have all focused on children with 'diagnosed asthma'. The intervention under investigation was usually delivered as an adjunct to the prescribed asthma therapy, and consisted largely of asthma specific information but often, included practical lifestyle changes to help avoid triggers. The outcomes were varied, and not perhaps the most helpful.

The most likely explanation for why the interventions were ineffective is that, with the exception of Wilson[58], the interventions were not based on theories of behaviour that were appropriate for the target populations, an issue that has been increasingly recognised as important[65;66]. Additionally, failure to tailor the intervention to the unique needs and beliefs of the target group, parents of young children with asthma, may have also affected outcome. What the review clearly highlights is lack of understanding around how best to supplement asthma care for the pre-school child. Thus it seems there is a similar level of uncertainty around education as exists for diagnosis and treatment.

Self-Regulation Theory

Self-regulation has been proposed as a means by which people can manage chronic conditions such as asthma, heart disease and obesity[67-70]. In this section a summation of how self-regulation has come to be so important in health, and in particular in the self-management of asthma, will be presented. It is not intended to be an exhaustive review of self-regulation rather a focused account of how the theory set the theoretical framework for this thesis.

The following section introduces the literature on self-regulation in terms of its theoretical origins, structure of the model and how it relates to disease management behaviour.

Definition

Self-regulation[1] has been defined as being observant and making judgements based on observation and then reacting appropriately to achieve a personal goal when attempting to change one's own behaviour[71].

Theoretical origins of self-regulation

The origins of self-regulation can be traced back to two important theorists; Albert Bandura[71-73] and Howard Leventhal[74;75], both psychologists. More recently the theory has been developed and adapted to health by Zimmerman[76;77] and Clark[67;78;79] both coming from the Bandura school, and Weinman[80] who has been influenced by Leventhal. This section traces the theoretical origins from Bandura and Leventhal to the subsequent development of the self-regulation model by the Zimmerman, Clark and Weinman groups [Figure 1].

Bandura

Bandura's self-regulation model has it roots in social cognitive theory, originally known as social learning theory. In landmark work in the late 1970's, Bandura began to define what today is recognised as social cognitive theory[71;72;81]. The theory was an attempt by Bandura to go beyond solely predicting behaviour and to describe the mechanisms by which individuals brought about personal change. Bandura was also central in bringing about the understanding of the connection between self-efficacy and self-regulation to define a unified theory of behaviour change[82].

Bandura sees everything through a 'social' context in which a person is influenced by the social norms (what does this mean?) within his/her circle of influence[83]. He defines human behaviour as a dynamic and reciprocal interaction of cognitive and personal factors, behaviour and the environment.

In social cognitive theory a person's behaviour is uniquely determined by the three factors, personal factors (i.e. the Self), behaviour and the environment. A

[1] Whilst in this study the emphasis is on the mother, she is regulating her own behaviour on behalf of the child. In this context it is indeed 'self' that is being directed. Therefore the term 'self-regulation' is used throughout the thesis.

key element of the theory is reciprocal determinism, a sort of two-way influencing process. In this a person's expectations, beliefs, perceptions and intentions give shape and direction to a behaviour, which in turn once carried out affects the person's thoughts and emotions.

Within social cognitive theory behaviour change/maintenance are a function of two sources: expectations about the outcome that will result from being able to achieve one's goals (outcome expectancies) and expectations about one's ability to engage in the behaviour (self-efficacy). The outcome expectancies relate to whether or not a given behaviour will lead to a specific outcome while self-efficacy relates to one's beliefs about how capable one is of performing the given behaviour.

Bandura argued that self-efficacy influences all aspects of behaviour, including the development of a new behaviour. Self-efficacy is learned from four sources: performance accomplishments, vicarious experience, verbal persuasion and physiological state, and refers to specific capabilities in specific situations. Performance accomplishments are thought to be the most potent source of self-efficacy, and derive from learning through personal experience. Personal mastery of a task or behaviour provides an increase in self-efficacy. If it can be achieved, once it can be done again. The more difficult the task achieved the greater the sense of self-efficacy. Bandura surmised that self-efficacy was behaviour specific. It varies with different tasks and challenges, and is not transferable from task to task.

Self-regulation is a construct of Social Learning Theory[71;81] and is seen as a means by which we can exercise control over our behaviour. As in social cognitive theory, Bandura saw self-regulation in terms of personal, behavioural and environmental processes[81]. In his model self-regulation is cyclical in nature, without a distinct beginning or end, rather consisting of several functional components that recur over and over again[81]. It is described as cyclical because feedback from prior performance is used to make adjustments to current efforts. Adjustments are necessary because the factors of influence on self-regulation change constantly during the course of learning and life. To counter this constant change, and to maintain the cyclical process of self-regulation, the factors of

influence must be constantly monitored. Without constant monitoring and reaction/adjustment to it, performance is only ever measured against an unchanging standard and whilst it may improve it cannot proceed to the next level. In this sense, it would become merely a competency, a repetition of a learned behaviour that then develops no further.

When related to health, Bandura's model assumes that people regulate their health through the use of self-care strategies by setting personal goals, and monitoring feedback concerning the effectiveness of the chosen strategies adopted to meet their goals.

Bandura's self-regulation process

Self-regulation is postulated to operate through a series of three sub-functions that are activated by the person. Bandura defines the sub-functions as: *self-observation*, *self-judgment*, and *self-reaction*[71][Figure 1]. Accepting that people cannot influence their actions if they are unaware of what they are doing, self-observation provides important background information necessary for the setting of realistic performance standards and for evaluating any change in behaviour or effect. Observing one's actions is an important step toward action, but alone is not sufficient. The judgment sub-function is influenced by the internal personal standards that a person holds and subsequently uses to judge whether a given performance is regarded favourably or negatively. Such standards are compiled by a variety of means, and influenced by the person's immediate environment. Developing observation and judgemental skills establishes the capacity for self-reaction. A person is motivated to be self-regulatory by a desired endpoint, or goal. The more desirable the goal, the more self-regulatory, the person is likely to be.

Summary of the key points from Bandura's self-regulation model:

1. Originally derived from Social Learning Theory
2. Self-regulation is a means to exercise control over behaviour
3. Behaviour is driven by goal setting and self-efficacy
4. Has three sub-functions; self-observation, judgement and reaction
5. Is cyclical in nature
6. Is underpinned by self-observation

Leventhal

Leventhal's self-regulation model was formulated to explain illness-related behaviour in chronic illness management, and incorporates his description of illness cognitions[74]. His model is based on the idea that people respond to changes in their health through a self-regulation processing system. In his model, the patient is conceptualised as a 'problem solver' whose coping behaviour represents a 'common-sense' response to their cognitive and emotional interpretation of experiences. Thus the representation or beliefs an individual holds about their illness influence their use of coping behaviours and their subsequent appraisal of the efficacy of the coping behaviours. Continuation of the behaviour is dependent on whether or not the person perceives it has worked.

How the patient conceptualises their illness (illness representation) is central to the model. Theoretically, a representation is created when individuals first notice a bodily sensation ("symptom"), which they may believe represents some malfunction or illness. These events are observed and interpreted by comparing them with one's or others' experiences (using a combination of information from one's culture, social communication and illness experiences). From a series of such events, an individual constructs a representation of an illness episode or problem and then creates a coping plan that may or may not include formal medical treatment. Leventhal suggests that illness representations are structured around five components: identity (nature of the disease), timeline (likely duration of disease), consequences, cause and amenability to control or cure.

Leventhal's self-regulation process

In his model there are three stages: *Interpretation* where information is analysed and given meaning; *Action or coping* where an appropriate response to the stimuli is organised and executed; and *Appraisal*, where the results of action are assessed in terms of the desired outcome [Figure 1]. The type of coping used is ordered by a cognitive or emotional interpretation to the response or trigger (symptom or message). The resultant behaviour is then continued or not, depending on the appraisal of whether or not it worked. The three components interrelate in an ongoing and dynamic way. The process is recurrent, with each illness episode providing additional informational input.

Different kinds of information and preparation affect the different stages, and operate through parallel routes. Leventhal proposes this happens through both subjective and objective processing of events, essentially emotional and cognitive responses. Irrespective of the type of processing that occurs, he states there is a hierarchical ordering (concrete, abstract). Much information processing happens automatically. In this situation, new behaviours can be performed automatically by inserting them within ongoing automatic sequences. Behaviour at any time, however, is likely to reflect both automatic and volitional processes. The system is perceived as a loop in which goals for action are set, with the system operating over time until the goals are reached. In Leventhal's model, three important principles play a part in the history of the development of self-regulation; (i) the characteristics of the system change over time (ii) new interpretations are added and (iii) the system develops into a more complex one. There is a dynamic element to the process, with growth and change over time. Temporal projections are built in such that perceiving an illness as acute implies brief episodes, whereas a chronic illness would be long lasting. When the process of self-regulation reaches the specified goals and the system stabilizes, the behaviours associated with it become less demanding and, in time, even automatic. Another important feature of an effective system is the negative feedback loop, that is, if the output does not meet the expectation attention is consciously directed to the system.

Summary of key points from Leventhal's self-regulation model:

1. Provides a means to explain illness related behaviour
2. Is underpinned by illness perceptions
3. Believes perception influences behaviour
4. Has three sub-functions; interpretation, action and appraisal
5. Is dynamic in nature
6. Rates monitoring highly

Having described the original sources of the self-regulation model the next section describes how it has been developed. There are three key individuals to whom further development has been attributed and are introduced [Figure 1].

1. Zimmerman, an educational psychologist, who originally adapted Bandura's model for use in an educational setting. Latterly, he has collaborated with health psychologists and clinicians.
2. Clark, a behavioural scientist, who has adopted Bandura's model in relation to the management of chronic disease by patients.
3. Weinman, a psychologist, who has developed the Leventhal model for use in the health care setting, through the development of quantitative questionnaires pursuing the relationship between beliefs and disease management behaviours, in particular, adherence to prescribed therapy.

Each individual interpretation is described, along with a description of how the model has been evaluated for use in research studies.

Zimmerman

Zimmerman's model is theoretically linked to Bandura with whom he has worked and collaborated closely [Figure 1]. He initially focused on self-regulation in the educational setting, in particular academic learning, but latterly has become interested in learning and behaviour change in health. Zimmerman identifies the human capacity to self-regulate as a critical factor in the survival of mankind by providing an ability to adapt and flourish even when adverse conditions threaten our very existence[84].

Zimmerman's self-regulation process

Approaching self-regulation from an educational perspective, Zimmerman proposes the self-regulatory process has three cyclical phases: *forethought, performance and self-reflection.*

Forethought refers to influential processes that precede efforts to act and set the stage for it. There are two distinct categories of forethought: task analysis and self-motivational beliefs. Task analysis involves setting goals (the specific outcome of performance the person desires). In highly self-regulating individuals, the goal setting is hierarchical with sub-goals and main longer-term goals. The sub-goals act as performance indicators, provide evidence of success and tend to increase the sense of personal investment in the whole process. Strategic

planning involves selecting learning methods that are appropriate to the task or skill to be mastered. Appropriately selected strategies enhance performance. Few strategies work optimally on all occasions, and as the skill develops the strategy may be changed.

Performance involves processes that occur during motor efforts and affect attention and action. Two types of performance processes are proposed, self-control and self-observation. Self-control helps learners to focus on the task and optimise their effort. Self-observation refers to a person tracking aspects of their performance, the conditions that surround it and the effects it produced. Self-recording is a common self-observational technique that helps to increase the saliency and importance of the feedback. Through such observations recurrent patterns (good and bad) may be seen. Examining regularities can help to identify influential factors (good and bad). This has parallels in asthma care where self-recording is a technique that has been used effectively by asthmatic patients and their carers[85].

Self-reflection involves processes that occur after performance efforts and influence how a person responds to the experience. The self-reflection in turn influences forethought regarding subsequent motor efforts, thus completing the cycle. The two main self-reflective processes are self-judgment and self-reaction. Self-judgment involves evaluating one's own performance and attributing one's own significance to the results (how important was the performance to self). Self-evaluation involves comparing one's self to a standard or goal. There are four main criteria that people use to evaluate themselves: mastery, previous performance, normative and collaborative. Mastery involves assessing one's performance against a set of scores/levels that usually spread from novice to expert. Previous performance involves comparing current performance with past, in effect an act of within subject (self) comparison. Normative criteria involve social comparison with others and collaborative criteria involve team effort and behaviour.

Summary of key points from Zimmerman's self-regulation model:

1. Applied to academic learning
2. Applied to learning in health e.g. asthma

3. Has three sub-functions; forethought, performance and self-reflection
4. Sees it in phases
5. Rates observation highly
6. Takes a 'process' approach to self-regulation

Zimmerman studies

Zimmerman has a well-established record of research investigating self-regulation. While much of his work has been conducted in the academic setting, he has also collaborated with researchers in health[85-86]. In his academic work, he has pursued tools to assess the process through which students self-regulate their academic learning. Zimmerman identified academic learners in general as 'self-regulators' because by entering a higher learning environment they had already chosen to be responsible for directing their own learning rather than relying on teachers and parents[77]. In this sense, they provided a good group on whom to start research on self-regulation. He went on to identify fourteen key learning strategies that students used to achieve academic goals on the basis of self-efficacy expectations[89]. Gradually, he has developed studies of how the process of self-regulation might develop in other groups. Three recent studies provide examples of how his research has progressed understanding of the measurement, and factors of influence, on development of self-regulation in health.

In 1999 Zimmerman was involved in a study which evaluated a new model for the development of self-regulation in parents of children with asthma[85]. The study was a collaboration with a well-known paediatric asthma research team who had experience in developing educational interventions for family management of asthma[90]. Drawing from his academic studies on the processes by which people become self-regulatory, and research in smoking cessation, he hypothesised that self-regulation could be mapped as a developmental behavioural progression. The group proposed a four-stage model for the developmental process parents of children with asthma might follow (1-asthma symptom avoidance, 2-asthma acceptance, 3-asthma adherence and 4-asthma self-regulation) to become self-regulatory. He developed a structured interview to evaluate progression through the stages. Families of 102 children with asthma from a Latino population in New York were recruited. The interview was administered over the phone by two bi-

lingual researchers and was recorded. The interview consisted of a series of questions, which the parents were asked to answer. The questions became progressively more 'self-regulatory'. Thus by stage four the questions focused on skills of observation, making judgements about initiating treatment and measures to assess success of any intervention, the three important sub-processes of the self-regulation model. The questions were grouped together to represent the four different stages. On completion of the interview, the recording was transcribed and scored by another individual. The questions were set as pass or fail. To progress to the next stage the parents had to pass the majority of questions assigned per stage. At the end of the study only two parents (<2%) had progressed to stage 4, full self-regulatory status. The majority (85/102, 83%) had reached only stage 1 and 2. It was not clear whether the poor levels of self-regulation seen were unique to the group studied or representative of the larger parental population.

In 2000 Zimmerman studied physical fitness of adolescent girls with and without asthma[88]. The study investigated the girls' self-efficacy in relation to their regulation of their physical activity, and self-regulatory practices in those who had asthma. Data were collected by questionnaire (for self-regulatory and self-efficacy information) and the Health Related Fitness test (for physical fitness). The questionnaire asked about asthma self-regulation in relation to use of specific methods for preventing acute episodes, recognising symptoms, and self-medication at the onset of an acute attack. Of the 135 girls aged between 14-18 years, 37 had asthma. Engagement with self-regulatory practices amongst the girls with asthma was found to be extremely poor, with only 2 of the 37 (5%) stating they had a plan to adjust their medication when their asthma worsened. It was also found that the asthmatic girls were less physically fit ($p<0.05$), had lower self-efficacy with regard to their functioning in vigorous activity ($p<0.05$) and participated less often in activities ($p<0.001$) when compared to the girls who did not have asthma. The authors had intended to analyse the relationship between asthma self-regulation and the other measures. However, as so little self-regulatory behaviour was evident this was not possible. Nevertheless, the study was one of the first to attempt to measure the degree to which adolescent girls with asthma were able to regulate their asthma. It confirmed a link between self-efficacy and self-regulation in relation to physical activity. It demonstrated that the

girls had low levels of self-efficacy pertaining to avoiding asthma symptoms combined with no self-regulation strategies to activate to avoid symptoms. As a result they restricted their participation in physical activities. The authors concluded that appropriate self-regulatory training and efforts to enhance self-efficacy were highly indicated. Despite the very small sample of girls studied the study highlighted extremely low levels of self-regulatory practices.

In 2001 he studied dietary habits in college students[86]. This study addressed the poor eating behaviours, namely diets that were rich in fat and sugar, commonly reported in students. In this study, the self-regulation model was studied in the context of 'behaviour change', and again included assessment of related self-efficacy. Students in both study groups received training in maintaining a food diary and calculation of dietary intake calculating daily energy, fat and fibre intake. Students were then randomly assigned to two groups, control (N=26) and intervention. The intervention group (N=113) was randomly assigned to one of four treatment groups: i) goal setting, ii) self-monitoring, iii) goal setting and self-monitoring and iv) no goal setting and no self-monitoring. After a relatively short intervention period (four weeks) the groups were compared. Goal setting and self-monitoring group was highly linked to successful dietary change and high self-efficacy. Students who did the combined activities consumed 91% more fibre and scored 15% higher on dietary self-efficacy. Self-monitoring alone was ineffective. Whilst self-monitoring is thought to be an important part of the self-regulatory process its non-effect in this study suggests that without an underpinning goal to provide a yardstick for comparison, self-monitoring is not activated fully.

Collectively, Zimmerman's studies show that in general self-regulatory activity varies across groups, and is often poor. Self-efficacy specific to the behaviour or task in focus increases self-regulatory achievement. Self-directed self-regulation, particularly out with the academic environment, is not common. However, with intervention self-regulatory practices can be enhanced, particularly if enhancement of self-efficacy specific to the goal in hand is included.

Clark

Clark's work follows on from Bandura's and has focused on assessment of the use and effect of the sub-processes of self-regulation, in disease management activity in particular for asthma and heart disease. Professor Clark has completed studies targeting children and adults with asthma and their carers. Bandura's influence in Clark's work is visible in her use of the same sub-processes of observe, judge and react [Figure 1].

Clark studies

In 1998 Clark conducted a study evaluating the impact of an interactive seminar based on self-regulation theory[57]. This study was unusual as it focused on changing specific aspects of physician behaviour, rather than directly targeting the family and child with asthma. It was a randomised controlled study of seventy-four general practice paediatricians working in two sites in the USA. The physicians were randomised to either control group or intervention group, which received the interactive seminar. The seminar assisted physicians to observe, evaluate and react to their own efforts to treat and educate their patients. Specifically, the seminar focused on helping physicians to create a therapeutic alliance with the asthma family, to give positive encouragement to the families efforts to self-manage, to develop the families skill in using the asthma medications, and to build their confidence to control asthma symptoms. The study's outcomes included physician behaviour (clinical treatment of asthma, patient-teaching and communication behaviour) as assessed by themselves and the families that they had a clinical contact with. The children of the families studied were aged 1-12 years of age, had been diagnosed with asthma, and had at least one emergency medical visit for asthma in the previous twelve months. Data were collected from the physicians (by self-administered mail surveys) and parents (by telephone interview) at baseline, at five months post seminar (physicians only), and post visit to the doctor for the parents (on average within two months of the visit). The findings showed that the physicians in the intervention group were more likely to address parents' fears ($p=0.02$), prescribe appropriate asthma treatment ($p=0.04$), and to write down information on how to adjust medication in relation to increase in symptoms ($p=0.001$) when compared to the control group. The parents' data confirmed the physician reports. Improved clinical outcomes were also noted in the children with asthma seen by the

intervention physicians with fewer reported visits for emergency asthma care. This study suggested that when physicians regulated their own asthma care-giving behaviour it was associated with improved clinical outcomes in their patients. What is not clear from this study however is whether the underlying model of self-regulation was directly responsible for the improvement or whether it resulted simply because more efficient, effective, clinical encounters had taken place. Nevertheless it demonstrates that the self-regulation model could be adapted in a novel way for use in clinical practice.

In 2001 Clark et al focused on self-regulation activity in American parents caring for children with asthma[67]. In particular they were looking for evidence of parental use of the three self-regulatory elements: observation, making judgements and reaction. The aim of the study was to test which elements were related, how stable they were over time, and which elements predicted outcome. They studied 637 children aged 1-12 years old (63% <8years old), with diagnosed asthma, and who had made at least one emergency visit for asthma within the previous twelve months. Data were collected by interview questionnaire, and parents were interviewed by telephone at three time points: the start of study, and at six and twelve months later. The interview questionnaire consisted of a series of questions covering the three model elements (observe, judge and react), factors of influence on self-regulating behaviour (internal and external) and asthma management strategies the families used (for example peak flow meters). It employed a structured questionnaire using a closed Likert-type response scale. The three self-regulation elements were significantly associated at each measurement point (baseline, 6 and 12 months later). The ability to make judgements correlated with efforts to observe the child in various asthma related situations (p=0.000). Making observations correlated with using more management strategies. Judgement, use of management strategies and judgement and confidence were strongly correlated. No other significant correlations were evident at each of three time points. There was no association between intrapersonal factors and other model elements. Baseline scores for self-regulation practices predicted health outcomes 18 months later. Higher baseline observation scores predicted higher quality of life scores in the child at almost 2 years later, and the greater the parental confidence in managing the asthma, the lower the use of subsequent emergency services.

This study had important findings. It showed that at least some parents were actively engaged in self-regulatory behaviours, and this positively affected clinical outcome in their children. What was not clear was how the parents had become self-regulatory in the first place when other studies had shown low levels of self-regulation[85;88]. However this may partly be explained by the fact that the 637 subjects were patients of the general practice paediatricians involved in Clark's earlier study (described above). These parents were not being assessed 'cold' as a number of them (not specified in the article) would have been treated by clinicians who had been exposed to an intervention designed to enhance their asthma self-regulatory care. Thus it is possible that the improved self-regulation skills in the physicians eventually led to improved self-regulation skills in their patients. It is not clear whether using Clark's interview in another sample population would produce the same results. Therefore while this study was extremely important in showing the positive benefits of self-regulation, and in providing a measurement tool, it has limited value in explaining the actual process of self-regulation development in the parents. It demonstrates Clark's focus on studying the elements of the self-regulation model.

In 2005 Clark et al described an intervention study from China[91]. The study was a controlled randomised evaluation of a self-regulation based asthma programme for school children delivered by their teachers. The intervention included training on observing signs and patterns of one's asthma, making judgements about using management strategies, using medications and identifying and controlling triggers. It was delivered to the children at school in groups of 20-25, in 5 weekly sessions. 631 (aged 7-11 years) children were recruited from 21 schools in two geographical areas; one industrial and one agricultural. The children were randomised within their geographical area to a control group, or intervention group who received the programme. Data were collected at baseline and one-year post intervention. Positive effects were seen in the interventions group children on school performance ($p=0.04$) and school absence attributable to asthma ($p=0.02$). Overall there was no significant difference in the number of emergency attendances and hospitalisations for asthma. However when considered separately intervention group children in the industrial group had fewer hospitalisations (in, $p=0.05$). There were no cases of children with severe

asthma in the study, which may have reduced the overall impact of the intervention since improvements in intervention studies are most often seen in children with severe asthma. Nevertheless, the study shows that elements of the self-regulation model when incorporated into an intervention can have on impact on some health care outcomes.

Clark has consistently shown positive effects for patients when using interventions based directly on the self-regulation model process. She makes a powerful supportive argument for the ability of self-regulation to improve asthma outcome. The studies have been well designed, most being of a controlled randomised nature with large numbers of subjects and relatively long follow up time periods, of usually at least one year.

Weinman

In Britain, Professor John Weinman's group has been responsible for expanding knowledge and application of self-regulation through the development of structured questionnaires to assess different elements of self-care[80;92;93]. Leventhal's model was attractive as a theoretical framework because it comprised illness perceptions and was developed specifically to explain illness-related behaviour. Weinman's studies have focused on adults, and have resulted in the development and use of two questionnaires; the Illness Perception Questionnaire (IPQ)[80;93] and the Beliefs about Medicines Questionnaire (BMQ)[92].

The IPQ was designed as an assessment tool for developing interventions to enhance self-management behaviour across a range of chronic illness. It is based on Leventhal's concept of self-regulation where patients' illness perceptions will predicate their behaviour. The BMQ was developed because the group believed that illness perceptions could also act as determinants of treatment adherence[92]. They hypothesised that self-regulating patients would have ideas not only about their illness but also relating to the treatment that was offered. They suspected that decisions around adherence to treatment would be influenced by the interaction between beliefs about the necessity of the treatment and concerns about the potential adverse effects.

Because Weinman has concentrated on questionnaire development his engagement with the self-regulation model is not directly relevant to the theoretical focus of this thesis, as it does not pursue the construction of the self-regulation model per se or provide information around how people develop self-regulatory practices in the first place. Rather his work is most useful in a situation where an individual is already highly self-regulatory, and adherence to treatment and/or illness perceptions are under investigation.

The studies that have included patients (adults) with asthma have shown that perception of illness is linked to beliefs about necessity of treatment and consequently adherence with prescribed regimes[80;94]. As a consequence patients who perceive their asthma to be acute/temporary see fewer serious consequences and have a low sense of beliefs around necessity to take medication.

Summary

As has been demonstrated there are many definitions and interpretations of self-regulation theory, making this area potentially rather confusing to the non-psychologist or non-behavioural scientist.

What the models all have in common is:

1. The models all place observation as being of critical importance. An individual must be adept at monitoring in order for self-regulation to occur.
2. Successful self-regulators are highly skilled at executing the sub-functions included in the self-regulation process - they track their behaviour (self-monitoring), they set proximal goals and draw from an array of strategies rather than relying on one technique.

Self-regulation and asthma seem to go together particularly well. Asthma itself is not generally fixed; it naturally fluctuates and changes, often in response to differing environmental and human states. It mirrors nicely the changing flux of the development of self-regulation; a variable disease occurring in a variable or dynamic environment. Additionally the literature provides a strong case for further exploration of the interplay between the two.

Relevance to Pre-school Asthma

Parents of young children with asthma have to act completely on a child's behalf. From the wider literature, it is known that how a person reacts to, and gives meaning to health and illness, can affect behaviour[95;96]. Therefore it seemed likely that this too might be important in parents of children with asthma. The next section focuses on the literature exploring what is known about how parents react to, and make sense of, asthma in a child.

The literature around illness behaviour is immense, with studies dating back to the late 1960's[95;97]. Much of it focuses on general health beliefs[98-102]. Today there is a wider recognition that patients' hold personal models of disease, which are comprised of illness meaning, knowledge, emotions, experience and beliefs, all of which influence behaviour[98;102-104].

The current study was interested in factors that might affect the asthma care-giving behaviours of parents and hence have potential influence or interaction on self-regulation development. Two groups of studies stood out from the literature as being of importance. The first, exploring Explanatory Models of illness, are limited in number, but were included because they offer a structured approach to study of how parents assign meaning to a child's asthma. Further, this approach was to become an important methodological tool in the current study. The second group of studies expanded understanding of how families experience and come to terms with asthma and its management, through qualitative investigation.

Explanatory Models

Explanatory models are a means by which an individual can make sense of an episode of illness and are largely attributed to Kleinman, a medical anthropologist[103-105]. They differ from general health beliefs, as they are specific to episodes of illness. Kleinman defines them as "Notions about an episode of sickness and its treatment that are employed by all those engaged in the clinical process"[103] page 105.

Kleinman developed his explanatory model concept through extensive fieldwork studies conducted in the early 1970's, in predominantly Chinese populations in

Boston, USA (1974) and Taiwan (1975). He was trying to extend understanding of the sickness and healing in society and its implications for clinical care by asking how and to what extent cultural and personal conceptions about sickness might influence the prevalence and course of particular disorders. He interviewed many groups of people, across a range of situations including:

- 150 families about sickness beliefs and responses to specific sickness episodes occurring in the family in the previous 1 to 6 months
- 120 practitioners and patients on practitioner-patient communications
- 100 patients treated by folk healers compared to 500 treated by western and Chinese style doctors,
- 25 Taiwanese with depressive syndrome
- And he observed clinical practice in 25 western-style doctors and 25 Chinese-style doctors

Through his work, Kleinmann has shown that study of patient explanatory models could tell us how individuals make sense of a particular episode of illness and how they choose, use, and evaluate care.

Three groups have used Kleinman's model as a framework for further study of childhood asthma.

Explanatory Models of Asthma

In 1987 Peterson et al combined Kleinman's[103] explanatory model theory with an ethnographic study of African-American families in Seattle and New Orleans, USA[106]. They were interested in the relationship between the families' meaning of asthma and their health care behaviour. The authors studied 20 adults who had a child diagnosed with asthma. The children were aged between 9-12 years, had a history of at least one previous emergency attendance for asthma, and were currently under continuing medical care/supervision. The parents took part in an interview based on Kleinman's methods, and were followed up monthly for one year. The interview was administered at follow-up visit 2 or 3, to allow a rapport to be established between the parent and the interviewer. The interview data was transcribed, coded and analysed prospectively. It was individually presented back to the family as their Explanatory Model at subsequent visits for additional

clarification and input. This process continued until no new information emerged, and indicated the point of censor for each study subject.

The findings from this study are of considerable interest because they show that the care the parents expected to receive for their children was directly linked to the meaning they had given to the illness in the first place. For example, the most commonly cited causes of asthma in the children were given as hereditary (60%) or linked to allergies (50%). Because the parents believed in these causes and thought they were important, they expected the health care professionals should address these specific cause issues for them. For example, one woman was still waiting after several years for 'testing' on the cause that she believed was responsible for her child's asthma. Further disparities between parents and care providers were observed. One example highlights the problem. A change in the weather was the most commonly reported trigger of asthma episodes in the children. Yet the medical care and advice promoted interventions against reducing exposure to house dust-mite, one of the least frequently reported triggers by the parents. The majority of the families (76%) called the condition asthma, and rated it at mild to moderately severe level. Parental assessment of severity was most often related to their ability to control symptoms, not frequency of symptoms which is a common basis of medical severity assessment.

The study showed that Kleinman's methods worked well when applied to asthma. The parents had attached meaning to the child's illness, and gave some insight to their expectations of care. It highlighted discrepancies between parental expectations of care and the care they received. Such information must be of importance in explaining why in part, some educational interventions for asthma fail. The study was not able to report on the actual behaviour the parents performed but nevertheless it gave valuable insight into the sort of beliefs, which might influence parental asthma behaviour.

In 2004, Handelman et al explored explanatory models of asthma in a group of parents (N=17) and children (N=19)[107]. The children in this study were recruited through clinics of a large urban paediatric hospital in Boston, USA. The children were aged between 5-12 (mean age 8 years), had moderately severe asthma, and had a history of at least one previous hospital admission for asthma. Data

were collected by interview, using ethnographic methodology. The interviews focused on explanatory model components of asthma aetiology, pathophysiology, chronicity and medications. The children and parents were interviewed separately, and all interviews were recorded for later transcription and analysis. The results between children and parents varied, for example 53% of the children ascribed their asthma to a contagious process, whereas 71% of parents believed it was hereditary. There was uncertainty across both groups regarding the persistent presence of asthma, that is, whether it was ever-present. 47% of mothers, and 53% of children, believed there was no asthma when the child was asymptomatic. As a consequence, the mothers chose to use the prescribed medication regime according to their beliefs. Those who believed the asthma had a variable presence also reported stopping the child's preventive asthma treatment at times. Unfortunately, in this study no quantitative data was collected to back up what the mothers reported, or how it affected subsequent health care use. In contrast, the Explanatory Models for asthma held by the parents were consistent with biomedical models, with 82% of parents identifying upper respiratory tract infections as the key trigger for the child's asthma. Nevertheless by eliciting the Explanatory Models the researchers gained some valuable insight into how beliefs about the asthma were driving medication adherence.

In 2002, Rich et al explored explanatory models of asthma and health related behaviours in 20 children and adolescents (mean age 15 years, range 8-25 years)[108]. Data were collected using Video Intervention/Prevention Assessment technique (a technique developed in visual anthropology) combined with qualitative inquiry techniques to analyse visual illness narratives collected over a 4-8 week period. The subjects recruited from primary care and hospital clinics all had moderate to severe asthma. Subjects were asked to create visual illness narratives to teach clinicians about their experiences living with, and managing, asthma. They carried camcorders recording their daily activities, dealing with various environments and people, in a sense cataloguing a snapshot of their life. Participants were given a series of open-ended guide questions as prompts to start their monologues and interviews with others. They were encouraged to explore a variety of asthma related issues, including the traditional causes, nature and prognosis. The narratives were catalogued, coded and assessed. Grounded

theory techniques were used to organise the data into key themes of illness experience. The video diaries proved to be a successful technique for collecting information from this age group, and the authors were able to report some key findings.

The findings showed that although phrased in the young persons own vocabulary their description of the nature of asthma bore strong resemblances to standard biomedical/textbook descriptions of asthma; for example, asthma was associated with bronchospasm, increased mucus production and inflammation. Whilst most participants and their families believed they had inherited asthma, for some the disease had connotations of contagion, punishment, the result of environmental effects or simply fate. A general fatalist view seems to run through the findings, with subjects preferring to take their chances with the consequences of asthma rather than engage in trigger avoidance or lifestyle change. All expressed a fear of death from asthma. Despite being able to identify their own triggers, few were able to control their asthma, and many deliberately limited their lifestyle. Medications were seen as the primary means of gaining control, despite the complications associated with regular adherence to asthma treatment.

Collectively, these studies demonstrate the usefulness of using an Explanatory Models approach in gaining insight into how individuals assign meaning and understanding to the asthma, and how it affects their use of health care.

Qualitative Study of Asthma from the parents perspective

Additionally a number of qualitative studies have enhanced understanding of the experiences of parents and caregivers involved in childhood asthma[109-116]. In general, such studies show that initially dealing with asthma is extremely hard for parents, but, that it gets easier with time[116]. They show that fear, lack of knowledge, concern regarding ability to manage the asthma, uncertainty about management and prognosis are some of what parents experience. Such findings are important as negative feelings, e.g. those of helplessness and uncertainty might inhibit confidence in dealing with the child's asthma. Low confidence, or a sense of low self-efficaciousness, if present, would make the development of self-regulation less likely.

Jerret and Costello investigated the process through which parents became competent in managing their child's asthma[109]. Thirty Canadian families with a child aged between 2-13 years were recruited. Data were collected by interview and analysed using grounded theory techniques. The findings showed that gaining competence and control of the child's asthma did not come easily. It involved a series of interlinked processes ranging from a state of helplessness and no control through to a state of gaining knowledge, ending with being in control. One of the important phases in the process was that of trying out different strategies to determine which might be useful. They mastered asthma management processes through a trial and error approach. They found this particularly difficult given the demands and responsibilities within the family. Over time the family adapted to the asthma, making lifestyle changes such as adopting the asthma regimes into daily life and limiting asthma triggers within the home environment. Through such processes the parents progressed to 'taking charge', which, represented the final phase of the theory of gaining control.

MacDonald conducted an in depth ethnographic study of eight mothers of Canadian children with asthma ranging from 3 to 10 years of age[111]. In total she conducted 13 interviews. She found high levels of uncertainty in the group. The uncertainty seemed to be linked to the fact that there was a delay between the mothers first noticing something was wrong with their child and receiving a diagnosis of asthma, and the fact that they could not with certainty assign a clear picture of how the asthma would progress. The situation only improved as the mothers gained mastery over the uncertainty.

Palmer studied ten care-givers of American children with asthma aged between 6-11 years in a grounded theory study[113]. She described a process, which she called becoming a vigilant manager, that the parents went through. The process which consisted of three parts; diagnosis, conflicts or battling, and resolution, started with receiving a diagnosis of asthma. For some of the families the diagnosis had been unexpected. The diagnosis phase was characterised by feelings of crisis and where a sense of 'not knowing what to do' dominated. Because they did not know what to do the families made repeated trips to the emergency room whenever the child became unwell. This became a battle they had to confront in order to gain resolution and undertake management of the

child's asthma. The parents rated gaining knowledge - that is knowledge specific to managing the child's asthma - as the most important strategy in resolution. This knowledge was not generally acquired from the health professionals but rather came through informal social networks, family, friends and other parents of children with asthma. Learning what to do was, mostly acquired through a trial and error approach.

Rydstrom conducted a grounded theory study with seventeen mothers of children aged between 6-16 years, with documented moderate to severe asthma[114]. Whilst this study was primarily looking at the dynamics characterising relationships within a family of a child with asthma it also offered some insight into the difficulties facing parents when coming to terms with managing a child with asthma. The mothers were all attending a hospital in Sweden for asthma care for their children. Data were collected by interview. The researchers found that uncertainty governed family life. The uncertainty arose from the unpredictability of asthma, with recurrent acute episodes, and related to whether or not they could manage the child's asthma. Degree of uncertainty was directly related to the state of the child's health, that is the more unwell the child was, the greater the sense of uncertainty.

Trollvik studied nine parents of five Norwegian children with asthma[110]. The children had moderate to severe asthma and were aged between 2-6 years. Data were collected by interview and analysed using phenomenological analysis. The parents were selected from a larger sample that had participated in an asthma education programme. The qualitative study was performed as an adjunct to gain insight into a parents' world when caring for a child with asthma. The findings showed the parents had experienced a process of chaos to coping. Initially they had experienced feelings of uncertainty and helplessness, and gradually moved toward a sense of coping through adapting to the asthma and eventually developing a series of coping strategies. The difficult feeling however would resurge every time the child became seriously unwell. The parents reported that they were more likely to try out strategies if they received support from a health professional. Whether this reflected a low sense of efficacy to start with is not explored in the study, but it seems possible it may have been involved. Again a

'trial and error' approach was seen, as the parents struggled to find ways of coping with the asthma.

Horner studied twelve American families with a school-aged child with asthma[115]. The families were recruited through nominations to the researcher from local physicians and paediatric nurses. Data were collected from three in-depth interviews, and analysed using grounded theory techniques. An overall process of 'catching the asthma before it got out of hand' was described. The process consisted of three overlapping phases; learning the ropes, dealing with asthma and coming to terms with asthma. The process began with receiving a diagnosis of asthma. When 'learning the ropes' parents started to observe asthma patterns, got to know the medication regimes, and made adaptations to family lifestyle and environment. With experience, and by developing a state of alertness, the parents became adept at using the medication to prevent asthma episodes. Again the results describe the parents progressing through a process. This study stands out as being very different as there was less emphasis in the findings on the difficulties that parents faced rather the focus was on practical adaptation to the new situation. In the absence of such difficulties the parents appeared to have made substantial progress in developing successful asthma management skills. The study showed that the meaning of illness changed over time for the families. Initially, pre-diagnosis viral illness was associated with recurrent viral colds; post-diagnosis these were recognised as being indicative of asthma exacerbation. At the start of the process the asthma was forefront in family life and a central focus. As parents' proficiency increased the asthma care became less dominant, and family life settled down and a sense of normality was achieved.

Callery et al explored beliefs about asthma within British families[112]. Twenty-five young people with asthma and their carers were interviewed using grounded theory techniques. The youngsters aged 9-16 years, had been diagnosed with asthma for at least one year, were categorised as having moderate asthma, were all receiving inhaled preventive therapy, and represented a deprived urban population. Two groups were sampled from primary (N=9) and secondary care group (N=17). Data were collected by interview. The subjects and their carer were interviewed separately at home, and encouraged to discuss the meaning of

asthma to themselves and their family. An early emergent category in the parents' narratives related to 'worry' associated with asthma attacks. The key findings centred on approaches to asthma management, objectives for asthma control, and assessment techniques. There were apparent differences in the narratives between the youngster and the parent. The youngsters tended to focus on the present, whereas the parents focused on past episodes often encountered during the child's younger years. The family management strategies described were not always similar to those recommended by health professionals, and could be described as conflicting. For example, the families describe trial periods off steroid treatment as means for assessing whether or not the asthma was persistent. While some carers described intervening early in an acute episode, many did not. Intervention was most often triggered by a more obvious severe deterioration. The main influence on action and important asthma decision-making within the group seemed largely to be drawn through 'trial and error'.

Barton et al studied twenty-one parents of children aged 2-14 years with asthma in Australia[116]. The qualitative study was part of a larger trial evaluating an educational intervention about asthma management being delivered to general practitioners. Data were collected by interview. The experiences of the parents were categorised in six themes; emotions and behaviours, coping strategies, disruption to activities, health and treatment beliefs, difficulties in asthma management and relationships with doctors. Underpinning the categories were fear, worry and uncertainty, driven by the unpredictability of asthma episodes. An important reassuring factor that emerged for parents was the knowledge that they could transfer responsibility to health professionals during acute exacerbations. The key finding was that over time things improved. Specifically the asthma became more controllable which was linked to the child growing older, and self-confidence in mastering asthma management increased over time. The parents' experiences and the meaning they had assigned to the asthma, impacted on their management. For example, at the start when they felt less confident the parents were reluctant for the children to be away from home. Additionally, during periods of wellness they reported altering medication doses, and on occasion not giving the prescribed medication at all.

Summary of the qualitative studies

All these studies, being qualitative, had small numbers of subjects and despite their wide geographical spread, may not be representative of larger populations. With the exception of Horner's study[115] they present a rather bleak picture of what confronts parents when asthma develops in their child.

Importantly, the studies provide information on the parents' experiences. A number of common themes emerge. Firstly, there is a sense of a developmental journey, which consists of different process parts. Secondly, a state of uncertainty seems to pervade the whole experience. The uncertainty reduces as things improve, but increases in response to deterioration in the child's state of health. The more acutely unwell the child is, the greater the feelings of uncertainty a parent experiences. In this sense, the state of uncertainty maps the unpredictability of childhood asthma. The overall situation tends to resolve when parents achieve practical mastery of strategies to control or treat the asthma, and/or as the child's asthma improves with time.

None of the studies have specifically reviewed their findings in the context of the self-regulation model yet elements relevant to self-regulation are clearly evident. These include lack of confidence and feelings of helplessness, which would map directly onto the construct of self-efficacy. Additionally, learning by trial and error, or a hit or miss approach, was used as the common way of learning, and is described in more than one study. This is particularly interesting as in Social Learning Theory, from which self-regulation derives, learning by 'trial and error', is recognised and whilst common, is viewed as a less effective way to learn[72]. Conversely, learning by 'vicarious means', using observation to learn is promoted as most efficacious. The parents gave the impression that learning had largely occurred without support from the health professionals, although detail around this was not forthcoming in the studies.

For this thesis, Horner's study is most interesting because again whilst it is not described in such a way, the parents in her study seem to be describing self-regulatory behaviour. This was evident in their use of alertness to identify when to use a management strategy (observation and judgement) and their refinement of

strategies (reaction) and a sense that over time this approach helped them gain control, as they re-used them.

If one relates the findings from the qualitative studies back to the theoretical content of the educational interventions described in the Introduction some anomalies are apparent. For example, in the main the educational interventions did not address:

- The meaning families attach to the asthma.
- The concept of a journey or process underpinning the development of asthma management skills.
- The extreme state of uncertainty and low confidence reported by the parents in the qualitative studies described.
- Development of self-efficacy in relation to specific asthma management skills or tasks.

It was clear to the present researcher that the literature review confirmed that the under five-age group of children with asthma were in particular need of further study. This was reflected in local clinical experience where admission data showed that this age group were high users of hospital services.

Having focused on the target group, the under fives, the next stage was to determine how to proceed. Previous research at the Royal Hospital for Sick Children Glasgow had focused on the development of educational interventions. Mindful of the high rate of failure of intervention studies in this age group careful thought was given as to how to progress.

How might models of self-regulation help

Two elements are known to increase the likelihood of an educational intervention being successful:

1. Basing it on a sound behavioural theory[66]
2. Adopting a systematic approach to its development[117]

Self-regulation was selected as the theoretical base for further study of asthma management in pre-school children because of emerging evidence around its success in improving health outcomes for asthma[57;91]. Additionally Zimmerman's

hypothesis that parents develop self-regulation through a developmental process[85] described in the Self-Regulation section accorded with the sense of process the parents in the qualitative studies had described.

The Precede-Proceed model is an extensive health education planning framework[118]. The model combines epidemiological, social, behavioural and educational perspectives, and consists of nine phases. Phase four relates to the educational diagnosis, which helps to define the desired outcome of the intervention. The purpose of the educational diagnosis is to identify the factors that are important if a person is to adopt, and continue with, a new behaviour. By studying the factors the clinician can decide which factors deserve priority in the educational intervention. The Zimmerman model, which assesses the development of self-regulation in parents by identifying particular asthma care behaviours, seemed a good fit for the task of educational diagnosis in the particular setting of pre-school children with asthma. Additionally, because we had no background information on self-regulatory skills in the Glasgow families attending the hospital it would provide an historical basis for later comparison.

At this point a study investigating the development of self-regulation in parents of young children with asthma was planned. An initial pilot study using the Zimmerman model to perform an educational diagnosis was devised. It was expected that this would provide background information that would underpin the development of a randomised controlled trial of an educational intervention for the parents of pre-school children with asthma designed to enhance self-regulation. The next section describes the pilot study.

CHAPTER 2. THE PILOT STUDY

This chapter describes a pilot study investigating self-regulation and self-efficacy in parents of pre-school children with asthma. At the time it was done, this study was expected to provide background information for a larger quantitative intervention study. However, as will be seen by the close of the chapter the results unexpectedly changed the direction of study. A description of the pilot study is included here because of its critical scientific role in defining the problem that led to a qualitative study.

Background

The introduction described how admissions for acute asthma exacerbations have risen substantially in children to become the commonest cause of admissions to paediatric units[119], a rise that has principally affected children under 5 years of age. Managing a pre-school child with asthma at home is difficult. Asthma medications are awkward to deliver to young children. Assessment is hampered because young children cannot explain how they feel and the usual home monitoring tools are not practical for young children. Learning how to manage a young child's asthma is a complex, practical task. The task is made more difficult because the fluctuating course of asthma means that parents use many of the skills only occasionally. Parents of pre-school asthmatic children therefore, have a particular need of support.

To manage a child's asthma successfully, parents have to assess and monitor their child's asthma, avoid asthma triggers and administer medication to maintain asthma control[87]. These behavioural processes are commonly referred to as self-regulation and are considered key for successful asthma managment[120]. While some families readily adopt such approaches, many do not. Such failures often result from internal barriers arising out of entrenched health beliefs and the existence of conflicting behavioural goals or priorities[85;121]. A further potential barrier is that many families are not taught self-regulatory techniques.

Drawing from research in smoking cessation, recent asthma studies have focused on the idea that self-regulation is the end result of a complex and

developmental behavioural progression rather than a simple educational process[85;121;122]. Zimmerman et al have proposed a four-stage model for the developmental process that parents of asthma might follow[85]. In the Zimmerman model, which is explained fully in the next section of this chapter, progression through the phases is determined by a person's ability to change fundamental beliefs about the illness, their self-perceptions of vulnerability, and a perceived self-efficacy for coping with symptoms. Self-efficacy in this setting is defined as a belief that one can carry out behaviours necessary to reach a desired goal[71;81;121]. Self-efficacy may be especially relevant to parents of young children because they are managing their child's illness and they may have a particular need to be confident before intervening on their child's behalf.

The relevant literature on the development of self-regulation and self-efficacy has been reviewed above and as noted above has proved limited. The available research has studied a range of age groups using different scales and techniques[123;124]. Many studies have been conducted in deprived inner city populations in the USA, often with multi-ethnic populations who do not have English as first language[85;125]. To date, no studies have looked specifically at self-regulation and self-efficacy in parents of pre-school children with asthma. Nevertheless, the wider paediatric asthma literature, which has not specifically focused on self-regulation, has clearly highlighted failure to follow an agreed management plan at the time of an impending asthma crisis as an important factor leading to hospital admission[126;127]. This finding provides indirect support for the suggestion that skills in self-regulation and self-efficacy are important factors in preventing unplanned emergency asthma contacts.

My previous research at the Royal Hospital for Sick Children, Glasgow had focused on the development of educational interventions for children with asthma. Zimmerman's model was of considerable interest as it offered a tool, which might measure the stage of parents' development.

A pilot study to investigate whether Zimmerman's scale could be used to categorise the behavioural development stage of parents of children with asthma was planned. The pilot study was funded from the Chief Scientists Office, Edinburgh, Mini-Project scheme [Grant ID: KOPR/15/11/F11]. At the time, the

researcher, P. Madge, was employed as a Senior Research Fellow. She was the principal investigator and oversaw all aspects of the pilot study. A researcher was employed for the day-to-day recruitment and data collection.

The Zimmerman Tool

Zimmerman's model posits that the development of self-regulation in parents of children with asthma is a sequential, incremental process with 4 phases. Phase 1 represents the starting point while Phase 4 represents attainment of fully self-regulatory status. Zimmerman assessed where a parent is positioned in the phase process through a structured interview, the Asthma Self Regulatory Development Interview (ASRDI)[85]. The ASRDI was designed for administration over the telephone. It was delivered by a researcher and tape-recorded for later scoring by another individual. It consists of a mix of sixteen statements/questions (11 statements for Phases 1-3, and 5 questions for Phase 4), grouped together to correspond to the four phases. A full explanation of the Phases and the Interview statements/questions follow.

The Phases

Each phase has a name and a descriptive explanation of what it is said to represent, along with some key identifying characteristics.

Phase 1 – Asthma Avoidance

> The parent tries to avoid asthma symptoms and to manage any symptoms that do occur in their child by using non-medical approaches such as restricting activities and controlling emotions (for example sitting the child down and stopping them laughing, in preference to giving asthma medication). At this stage, the parent deals with asthma episodically and does do not attribute the symptoms to a chronic underlying disease.

Phase 2 – Asthma Acceptance

The parent accepts asthma symptoms as a manifestation of an inherent physiological vulnerability. The parent accepts that it is serious, but responds reactively, relying on emergency medical contacts for rescue treatment. They believe the asthma goes away when symptoms fade.

Phase 3 – Asthma Adherence

The parent now deals with asthma as a chronic condition but lacks confidence to self-regulate because s/he is unskilled in adjusting medication to control asthma and preventive attacks. The family seeks to prevent and control asthma symptoms by following the physician's treatment recommendations and the child is less likely to need emergency treatment.

Phase 4 – Asthma Self-regulation

The family develops an adaptable medical plan in consultation with a physician; they can identify early warning signs of inflammation; they adjust the medication regimes on the basis of monitored symptoms; they set high goals and are confident of their ability (self-efficacy) to implement the plan and contact their doctor when modifications are needed.

Interview Structure

The interview has sixteen mixed statements and questions. Each Phase has a specific number allocated to it. For example there are five statements for Phases 1 and 2, six statements for Phase 3 and five questions for Phase 4 [Appendix 1]

The statements/questions reflect the different phases.

For example, Phase 2 (representing acceptance of asthma) requires that a parent must adopt the belief that asthma is a serious, long-term condition. Therefore, the statements in this section reflect such ideals.
An example one of a Phase 2 statement:
"*Your child could wake up one day without asthma and never show signs of it again. Do you agree with this? Why?*"

An example of a Phase 3 (representing asthma compliance) statement is:
"Some parents feel that if their child's asthma medicine seems to have worked they can reduce the dose or stop using it altogether. Do you agree with this? Why?"

The interviewer reads out the statements and the interviewee replies. The interviewer must not discuss any of the statements or change the wording. They are only permitted to explore for further clarification or meaning. The interview is recorded for later scoring by another individual.

Interview Scoring

A person other than the interviewer scores the interview. They do this with the aid of a scoring key [Appendix 2]. For each statement, there are explanatory criteria and a list of 'Pass' and 'Fail' codes. The recorded interview is played back and the scorer allocates a pass or fail according to the responder's response to each statement/question.

For example in Phase 4 the parent is asked:
"Do you have special methods to check for early signs of an asthma attack coming on? What are they?

In order to 'pass' this question the responder would have to indicate that yes, they did have special methods, and give examples. An extract from the scoring key for this Phase 4 question follows:

Pass	Fail
Describes specific early symptoms related to onset of attack	Notices only when symptoms are severe (e.g., heavy coughing, gasping, noisy breathing)
Describes increased monitoring whenever there is a correlative condition (e.g., having a cold)	Aware of correlative condition (e.g., flu season) but doesn't specify any indicators to monitor
Says something like: "First symptom is the runny nose then it's the cough, wheezing – that's when I start with inhalers to prevent it going further"	

In the original study, the ASRDI was administered by two researchers and scored by two 'blinded' adults. The interviewers had no access to the 'answers'. The scorer played back the recorded telephone conversation and scored each response accordingly. On completion, the statements/questions for each phase were tallied and the phase allocated. Responders are assigned a phase depending on the point they fail a phase set of statements/questions.

If the responder passes the majority of the first five questions, they reach Phase 2 (Phase 1 and 2 are scored together as the first two questions represent Phase 1, which is seen as a base level of functioning). If the responder passes the majority of the next six questions, they reach Phase 3. If they pass the final five questions they are classified as Phase 4. To be identified as fully self-regulatory, the interviewee must have passed the majority of statements/questions throughout the three sections.

Hypothesis

The hypothesis of the pilot study was that parents of pre-school children with asthma presenting for emergency asthma care may not have mastered the necessary SR skills.

Aims

A pilot study to investigate whether self-efficacy and self-regulation were deficient in parents of pre-school children with asthma presenting to hospital was planned. The overall aim of the study was to assess levels of self-regulation and self-efficacy in parents of pre-school children with asthma presenting for both emergency and scheduled asthma care. Three specific aims were identified:

1. To assess use of the Asthma Self-Regulation Development Interview in a group of Scottish parents of young children with asthma.
2. To investigate levels of parental self-regulation and self-efficacy in the immediate period around an emergency department visit or hospital admission because of an acute asthma exacerbation.

3. To compare self-regulation and self-efficacy in a second group of parents of pre-school children attending a specialist asthma clinic who were not having frequent emergency contacts or admissions because of asthma.

Methods

Subjects

The pilot study was performed at the Royal Hospital for Sick Children in Glasgow in the five months between May and September 2000. Parental self-regulation and self-efficacy were investigated in two groups of parents of pre-school asthmatic children:

1. Group 1, comprised parents of children admitted to hospital or seen in the Short Stay Ward with an acute exacerbation of asthma.
2. Group 2, comprised parents of children attending the specialist respiratory clinics who had had no asthma admissions or emergency attendances.

Parents were eligible for inclusion in the pilot study if their child:

- Was aged between 1-5 years *and*
- Had a diagnosis of asthma (acute wheezing with definite response to high dose bronchodilator therapy Group 1 only) *or*
- Had a documented medical diagnosis of asthma, and a history of previous obstructive respiratory symptoms (Group 2)

Recruitment & Sampling

All admissions into the Short Stay Ward at the Royal Hospital for Sick Children, Glasgow were monitored on a daily basis (Monday to Friday). Clinic lists at the weekly respiratory clinics were examined in advance by the Research Assistant to identify children fulfilling the entry criteria. The parent, with primary responsibility for the child's asthma care, took part in a 30-minute interview using two published scales for measuring self-regulation and self-efficacy.

All eligible parents were approached by the research worker and invited to participate in the study. If they agreed, written informed consent was sought prior

to data collection. The study was reviewed and approved by the Ethics Committee of the Royal Hospital for Sick Children, Glasgow [Appendix 3].

Measures

Self-regulation was assessed using the Zimmerman interview, which investigates the development of asthma self-regulatory skills. As before, the interview had been validated for use in parents of children with asthma, including some pre-school children and some children with acute asthma. It was recommended that it be delivered by a researcher, tape-recorded, and then rated from the recording by an independent assessor. We used the same technique with the researcher P. Madge as the independent assessor rating the interviews. The Research Assistant conducted the interviews, which were recorded and later transcribed and scored by P. Madge. In this study, the ASRDI was administered face-to-face and recorded by a minidisk player.

For self-efficacy the scale of Bursch et al was used[123]. This is a parent-completed questionnaire, which measures three dimensions of parental asthma management: parental belief in treatment efficacy, parental barriers to asthma management and parental asthma self-efficacy in relation to attack prevention and attack management. The scale has been validated for use in parents of children with asthma, including some pre-school children and some children with acute asthma.

Statistics

Data were summarised using standard descriptive statistics, and analysed with chi-squared tests and Mann Whitney tests (respectively) to compare the distributions of discrete and continuous outcome variables in the two populations of parents. All of the statistical testing for the study was undertaken by Dr John McColl, Department of Statistics, the University of Glasgow.

Piloting of the Measures

The first six weeks of the study were devoted to the training of the research assistant and the piloting of the assessment measures, under the direct supervision of P. Madge. The ASRDI interview was piloted to allow the complete

process of interviewing, recording, and post-test rating from the recorded interviews to be tested. During this time, eleven pilot interviews were performed to ensure that the methodology was measuring what was intended. Some minor changes were made to some of the questions in the ASRDI. These changes did not alter the focus of questions but took account of the local variations in language. For example the term 'Emergency Room' was changed to 'Casualty'.

The ASRDI was scored according to the Zimmerman method. The whole interview transcript was listened to and each question was scored as pass or fail. A phase was then allocated. It was noted at the end of the pilot that two subjects had failed at Phase 2 but passed at Phase 3 and 4 respectively. At this stage, P Madge was concerned that an error had been made in the scoring. She contacted one of the Zimmerman group co-authors (S Bonner) as the individual responsible for the ongoing development of the ASRDI. The interview coding sheets used were reassessed, no obvious errors were identified and given the small numbers involved the fails were upheld and no further action was taken.

Results

Subjects

After testing of the data collection measures, 48 parents were recruited and interviewed (M:F ratio 8:40). Of the 48 parents recruited, 21 had a child in the short-stay ward (M:F ratio 4:17) as a result of an emergency asthma admission and the other 27 (M:F ratio 4:23) had an appointment at an outpatient clinic.

Measures

Self-regulation and self-efficacy were measured in both groups. Some technical problems were encountered. The microphone failed to record the first two interviews. A new, superior, microphone was purchased and no further recording failures occurred.

Levels of parental self-regulation

In both groups the majority of parents failed to reach Phase 4 [Table 1]. There was some evidence that parents of children in Group 1, recruited from the Short

Stay Ward presenting acutely, had generally poorer self-regulation skills than parents at the clinics but this difference was not statistically significant (p=0.16).

Levels of parental self-efficacy

No differences in overall self-efficacy between the two groups were detected, although parents in the outpatient group had a significantly higher belief in treatment efficacy than the Short Stay Ward parents (p=0.005) [Table 1].

ARSDI Scoring discrepancies

Mindful of the discrepancy noted in the early piloting the scoring of the ASRDI was closely reviewed on completion of the pilot study. Again it was noted that a number of subjects (10/48), had failed to pass Phase 2 but had then passed Phase 3 (N=8) and Phase 4 (N=2).

There was no obvious explanation for why this might have occurred. In the Zimmerman model Phase 2 represents asthma acceptance, Phase 3 asthma compliance and Phase 4 asthma self-regulation. It seemed possible that although some parents had not fully accepted the diagnosis (phase 2) they were actively engaged in giving the prescribed treatment regimes to their children. The interview scoring was checked and confirmed by another member of the study group.

Overall this finding raised concern regarding the reliability of the ASRDI to capture accurately and stage the processes of behavioural development that the families were making. It seemed unwise to progress to a larger study of improving self-regulation skills if the proposed scale for assessing self-regulation was not performing satisfactorily.

Discussion

The Zimmerman group drew on many years of experience and expertise in paediatric asthma research in the development and testing of the ASRDI. They paid particular attention to detail in the construction of the statements and questions, and rigorously tested them on the public. They used recognised analysis techniques to test both the individual factors and the sequential

properties of the model. In Zimmerman's original article they had reported a small number of subjects, who failed Phase 2 but passed Phase 3. They chose to classify the subjects in the higher phase because they had in fact passed Phase 3 criteria.

Overall, it seemed to the present researcher that, for most subjects, the ASRDI was capturing some aspects of the development of a complex behaviour. However, in the light of a small number of anomalies in terms of progression from one phase to the next, it was felt that it could not be safely assumed that the model was a complete fit for all examples of development. As a number of parents had passed a later phase having failed a preceding phase, it was speculated that the order of the phases might be incorrect. However, without further study it was not possible to determine from the pilot study where any potential flaws might lie. Another speculation considered the possibility that the underlying theoretical behavioural approach used in the model was wrong. The model assumed that the development of self-regulation followed an incremental process of change. Managing asthma is largely about learning new things and new behaviours, and in fact little is known about how parents of children with asthma develop their skills as there have been no long-term observational studies. It was clear from the pilot study results that initial predictions drawn from Zimmerman's model e.g. high self-regulatory status equals child's asthma under good control, were not confirmed. The disappointingly low levels of self-regulation in the Glasgow parents, and the lack of difference between the two groups studied, highlighted how much remained unknown around this topic.

The pilot study had clearly exposed uncertainty and halted earlier plans for a further quantitative intervention study. It became clear that a better understanding of how parents developed self-regulation skills was needed and it was this requirement that led directly to the qualitative exploration of the development of self-regulation in parents described in the present thesis.

The following chapter describes how the author progressed to the qualitative exploration of the development of self-regulation.

CHAPTER 3. METHODOLOGY

This chapter outlines the aims and objectives of the study and the research design. Grounded theory[128] was the qualitative research method chosen for this study, with transcripts of interviews providing the data for analysis.

In the previous chapter a problem was noted in the Zimmerman self-regulation assessment tool. This discrepancy, combined with the generally low levels of self-regulation found in parents who appeared to be keeping their children out of hospital, suggested that the model underpinning the Zimmerman scale, which suggested a linear progression, might not match how the developmental process progressed in real life. If this were so, further research with an alternative method of assessment would be required. In order to expand understanding around development of self-regulation in carers, the present study was planned. It was considered that a qualitative approach would be the most appropriate method to investigate further this aspect of parental self-regulation.

Rationale for a qualitative interview study

In the current study, a qualitative approach based on individual in-depth interviews for exploring mother's development of self-regulation skills was selected for two reasons.

Firstly, a qualitative approach was felt more likely to be successful in accessing the underlying process that occurs when a mother confronts the diagnosis of asthma in her child. Secondly, qualitative semi-structured interviewing is a well-established research tool in sociology and related disciplines[129-132]. As an approach, it is particularly well suited to parents of young children[133-135]. Interviewing can be a powerful way of helping people to articulate hitherto unspoken perceptions, feelings and understandings and also allows immediate clarification of issues as they are raised[129;131]. Qualitative research has not traditionally been a popular investigative method within scientific research fields because it is time-consuming and, for those trained in conventional scientific approaches, does not produce numerical results suitable for statistical analysis. However it is increasingly clear that qualitative approaches can provide insights into 'why' an event or process happens. In the area of health service research,

such approaches may be valuable in understanding why particular patients respond and behave in particular ways, and what effect their beliefs and assumptions have on their behaviour.

Aims

The study planned to conduct a qualitative interview-based study using the principles of grounded theory to explore the following research questions in a group of mothers who had a child diagnosed with asthma and were attending the Children's Hospital.

1. To explore the circumstances surrounding the emergence of asthma in the young child, in particular:
   Under what conditions did asthma present?
   Were any barriers to diagnosis encountered, and if so how were they overcome?

2. To explore any evidence of self-regulatory thought or action, in particular:
   Was there any indication of how self-regulation developed?
   What factors were associated with the development of self-regulation?
   Was there evidence that the mothers were following a self-regulatory model for managing their child's asthma?

3. To explore the beliefs of the mothers around asthma, in particular:
   What caused the asthma?
   What influence did the beliefs the mothers held about asthma have on their self-regulatory behaviour?
   To explore to what extent the mothers' beliefs about asthma concur with a biomedical model?

Qualitative approaches commonly used

There is now a range of qualitative approaches available with increasingly well-understood rationales, methods and forms of analysis. These include methods such as group interviews (focus groups), individual in-depth interviews, observational (ethnographic) research or organisational case studies[128;130-132;136-139].

There are at least three qualitative research approaches that are appropriate for data gathering from single subjects: ethnography, phenomenology, and grounded theory[130;132;140]. The particular approach used depends on the ability of the approach to answer the research question being posed[130;136]. These qualitative approaches all use a field-based approach based on a researcher using observational techniques and /or interviews. Each approach was considered for its usefulness and appropriateness in relation to the purpose of the current study and its aims and objectives, and the fact that the researcher whilst experienced in health service research did not have a background in sociology, the discipline in which the qualitative methods are rooted.

Ethnography

Ethnography has its roots in anthropology and is primarily concerned with cultural influences[132]. By being informed by culture, it offers a way to understand how members of a community construct their world. As such, it is an appropriate approach for understanding illness behaviour through understanding the culture of its recipients. Ethnography is characterised by a lengthy period of involvement and observation of the subjects, in which the researcher's position should be neutral, reflective and documentary. The observer gains an insider's view through rigorous observation over time. In this approach, the collected data might include quotes, stories, legends, folklore, and visual representations of culture.

Asthma, as far as is known, is fundamentally a pathological as opposed to a cultural phenomenon; it crosses all cultures and geographical boundaries. In addition, the prolonged, detailed period of involvement with the subjects that is the hallmark of an ethnographic study would not have been possible within the resources and time-scale of the present study.

Phenomenology

Phenomenology was founded as a philosophy and research approach by Husserl[141;142] and has been widely applied in philosophical research. It studies the subjects' perspectives and philosophical stance on their world. By detailing the content and structure of a subject's consciousness, it tries to tease out the essential meanings of the subjects' actual, lived experience. It is particularly useful when trying to gain understanding from the field without any constraints from pre-existing theoretical frameworks[130;132]. It is usually based on fieldwork, most commonly interviews.

Practical application of phenomenology is complicated, and it uses a highly specialised vocabulary. Some grounding in philosophy is desirable. Whilst some readily available step-by-step simple guides are available[143], there are considerable barriers for the qualitative researcher to using the approach. Importantly it may produce an accurate but very 'individual-specific' meaning.

Grounded theory

The third common qualitative approach, grounded theory, was developed by two sociologists Glaser and Strauss in the 1960s and has become an increasingly popular method for qualitative analysis in health service research. Its theoretical underpinnings lie in philosophy and sociology[128]. The phrase "grounded theory" is used to indicate that the approach was derived from data systematically gathered and analysed through a research process[138]. It is described as an analytic, inductive technique - that is, it progresses from observation, to the development of a theory or model of action in a rigorous manner. It is designed to generate explanatory models of human behaviour which are grounded in the data[130]. Whilst complex, it has been widely used in nursing research and there is a large literature describing its use in practice[144]. It works well with data collected through interviews and issues surrounding 'process, stages and changes over time'[130]. Grounded theory is not, however, without its critics[132;145]. It has been criticised for its lack of generalisabilty and its ordered 'process-like' structure. For some critics, the process-like nature of grounded theory contradicts a central tenet of qualitative research where the experience of the participant takes priority over the interpretation of the investigator[146].

Rationale for using grounded theory as main influence

Using grounded theory methodology to direct data collection and analysis was decided upon for three reasons. Firstly, it was considered to be most appropriate for obtaining a detailed understanding of how the experience of developing asthma had influenced the mothers' development of self-regulation and the influence that any lay beliefs might have had on the process. Secondly, it has been considered particularly appropriate for areas where there is a degree of uncertainty, and when the research question pertained to understanding or describing a particular event, topic issue or phenomena[130;132]. The main strength of this approach lies in its inductive nature, with hypotheses and theories emerging from the data set[147] rather than being imposed on it. Finally, whilst it is based on social constructions it is the most accessible method to researchers from a non-sociological background, and therefore was considered the best choice for the current study.

Therefore, in the present study, grounded theory methodology was selected as the main qualitative research approach because of: (i) its capability to draw theory from the data - that is, to explain what is core/central in the data (as an analytic inductive technique); (ii) the fact that it follows a systematic approach; and (iii) because of the absence of an existing framework within which to study mothers' self-regulatory development regarding their child's asthma.

In this study, the influence of grounded theory is identifiable in the processes that were used. These include theoretical sampling; coding procedures; memo writing; use of a constant comparison method; and ending data collection when theoretical saturation was reached. The methods used in the study sit comfortably with Strauss and Corbin's fundamental premise that concepts be allowed to flow from the data[138].

Strengthening Qualitative Studies

Criticism of methodological rigour of qualitative research has led to measures of assessment against which qualitative work might be judged[137;148-151]. Whilst the principles of grounded theory were used to inform study design and methodology, key points (following) from these reports were used to strengthen rigour and

validity followed by a brief description of where these points are visible in the present thesis.

1. Participant selection must be well reasoned and their inclusion must be relevant to the research question
2. Data collection methods must be appropriate for the research objectives and setting
3. A clear exposition of the procedures and process by which data were gathered must be comprehensive enough to support rich and robust descriptions of the observed events
4. Findings must be adequately corroborated using multiple sources of information to establish whether viewpoints were adequately interpreted
5. Data must be appropriately analysed
6. A clear exposition of how early classification evolved into the sophisticated coding structures must be provided
7. Data relevant to each category are subjected to the constant comparison method
8. There will be a chain of evidence from extracted themes and interpretations back to the original transcript, which is accessible and evident to an external audit

Collectively, the eight points affect both data collection and analysis processes. Therefore, in this thesis, they are visible in both the current and subsequent five chapters. For example points 1, 2, and 3 are addressed in the current chapter (Methodology). Point 4 is addressed in the chapter called Triangulation. Points 5-8 are most pertinent to the qualitative results chapters. Therefore, at the start of each results chapter a short introductory section of how the themes appeared in the transcripts is provided. A deliberate decision was made by the researcher to present the findings in this way in order to provide the qualitative analysis with as high a degree of transparency as possible, as well as to maintain a natural flow to the thesis narrative.

Participant Selection

Sampling in grounded theory

In the present study, the sampling was influenced by principles of qualitative research and grounded theory[130;136;138;139]. In qualitative research, sampling is based on adequacy and appropriateness[130]. This differs fundamentally from quantitative research, which is statistical in approach and largely concerned with addressing whether the sample is representative of the whole population[152].

In a qualitative research context, appropriateness refers to the identification of individuals who can best inform the theoretical requirements of the study[130]. Adequacy refers to the need to ensure that there are sufficient data to provide a full and rich description of the phenomenon[130;138]. Both these terms carry the implicit assumption that the subjects selected have experienced the phenomenon under question and will have meaningful experiences of it to share.

In general, sample sizes in qualitative studies are smaller because of the time needed to collect, process and reflect on the data collected in detail. In grounded theory, sampling is non-linear, the sample size is never pre-set but rather is directed by on-going analysis and reflection on the data already collected. Sampling starts in a purposive manner with participants judged to be relevant to the research questions being identified[138]. Analysis begins early in the data collection process and the two processes of data collection and analysis work in alternating sequence, an approach commonly referred to as 'constant comparison'[138]. In practice, this means that analysis starts as soon as the first interviews are performed. The early findings from the analysis then influence both the subsequent interviews and future subject selection (leading to theoretical sampling). The first few interview transcripts are examined in detail to establish analytical categories designed to correspond to the research questions.

This stage of analysis is then used to direct further data collection, helping to refine the initial categories, to explore emerging concepts (axial coding) and to define subsequent sample selection. However, sampling quickly becomes theoretical, which Strauss and Corbin 1998 define as

> *"Data gathering driven by concepts derived from the evolving theory and based on the concept of making comparisons, whose purpose is to go to places, people or events that will maximise opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions"* [138] (page 201).

In practice, this leads the researcher to focus on theoretically useful cases that are likely to extend the emerging categories. The grounded theory researcher seeks further subjects in order to add to the fullness of the understanding of a concept. Strauss describes seeking samples, populations, events, activities, in order to answer questions like:

> *"Where can I find instances of 'x' or 'y'?"*[139] (page 16)

Participants are chosen as needed, in order to follow specific leads or experiences. The constantly modified categories act as sensitising devices to inform the collection of data, and are, in turn, constantly re-assessed using the constant comparison technique to see how they stand up over time. The researcher continues selecting participants using theoretical sampling until the new samples provide no new information about the concepts being explored. This is often referred to as "theoretical saturation". At this point, additional sampling and data analysis no longer contributes to discovering anything new about a category[139] (page 21). The advantage of this method is that a transparent audit trail leading from the final category or theme back to the raw data is evident. This audit trail helps strengthen the credibility and reliability of the final results[148].

Sampling procedure employed in current study

In keeping with grounded theory sampling, the current study began by identifying asthma criteria relevant to the research questions and the population that was to be the focus of the study. These became the study inclusion criteria. The inclusion criteria for participants in the present study were that they would be mothers of children:

1. Aged between 1-5 years
2. Diagnosed with a documented medical diagnosis of asthma, and a history of previous obstructive respiratory symptoms
3. Currently, prescribed asthma prophylaxis

4. Not currently taking part in another research study

It was decided to target only mothers because they generally identify themselves as the main asthma carer in a family[18]. The lack of male participants was not seen as a disadvantage as the study was not planning to address issues of gender in relation to development of asthma management practices. Further, in clinical practice, mothers are the adults who most consistently accompany their children to outpatient clinics where it was planned that recruitment would take place.

Recruitment took place in the paediatric outpatient clinics. There were two reasons for this. Firstly, this was an approach that had worked well in two previous studies conducted by the respiratory team. Secondly, because clinics are planned in advance, it allowed a more structured approach to recruitment. Clinic lists could be screened in advance to identify potential participants. Alternatives, such as recruiting only inpatients would have been more haphazard, and would have resulted in subject recruitment taking longer.

Identification of Subjects

Having defined the initial inclusion criteria, a strategy was developed to identify eligible children and their mothers. Different approaches were used for the purposive and theoretical sampling. Both however, were in line with ethical requirements on recruitment of families into research studies within the hospital.

For the initial purposive sampling (from clinic lists)

For the purposive sampling, case records of children attending the weekly respiratory clinics were examined to identify children who satisfied the initial inclusion criteria. There was no restriction relating to social background and the children identified were from across the socio-economic spectrum [Table 2]. Two approaches to recruitment from the clinic were used.

(a) Identification 'in advance'

Lists of children booked in for all out patient clinics are stored on the hospital's computer information system. These can be accessed in advance to see who is

scheduled to attend. One week in advance, the researcher would download the clinic lists for the four respiratory clinics, which occurred each Thursday morning in the out patient department. The lists only give the child's name and hospital number. Further detailed information was available in the child's case records, which were obtained from medical records department. Since not all children attending would have asthma, the medical records of all children scheduled to attend a forthcoming clinic were reviewed with the goal of identifying one potential recruit each week.

Having identified a potential participant, permission was sought from the relevant consultant to approach the family. No consultant declined. A copy of the study 'introduction letter', a letter from the consultant and researcher, [Appendix 4] and study information sheet [Appendix 5] were posted to the family. Sending the material in advance of the scheduled clinic appointment allowed the family sufficient time to consider whether they wished to participate or not. On the day of the scheduled appointment, the child's consultant was reminded by the researcher to raise the issue of the study during the consultation. If the family accepted the consultant's invitation to take part, the consent process was completed at the end of the appointment in their first face-to-face contact with the researcher. At this point, formal written informed consent was obtained and the necessary arrangements for the study visit were made. This approach was successful but labour intensive and it did not yield a large number of participants.

(b) Identification 'on-the-day approach' – used latterly

To reduce recruitment time, the 'on-the-day' approach was developed. The researcher would visit the respiratory clinics on the day of the clinic to ascertain whether any child attending fitted the inclusion criteria. If a suitable participant was identified, the consultant was alerted prior to the consultation commencing. During the consultation, the study was introduced to the family who were provided with the written study information. If they were interested in considering participation, the researcher was introduced to the family at the end of the consultation. The researcher arranged a suitable time to call the mother, usually within 7 days, to follow up on the invitation to participate. This again ensured the mother had adequate time to consider whether she wished to participate. If, in the follow-up telephone call, she agreed to participate, a mutually satisfactory time

and place for the interview was agreed. This was usually arranged at her home. To complete the consent process, written consent was obtained at the start of the home-visit. This approach was successful and efficient. Only one mother declined to take part at the follow-up phone call stage - a single mother who mostly worked nights in a local bar who said she was too busy.

For the theoretical sampling (gate-keeper approach)

In accordance with grounded theory, after the first few interviews, the transcripts were examined and analysis commenced. As the initial analytic categories were established, a more focused sample was needed. This signalled the start of theoretical sampling. In order to widen the pool of participants sampling was extended to include both clinics and the inpatient wards.

Examples of emergent categories and influence on theoretical sampling:
Example 1.

Early on in analysis, the respondents described difficulty, uncertainty and delay around receiving a diagnosis of asthma from the General Practitioner. In order to pursue this theme, the researcher had to find mothers who had gone through similar experiences. Case notes of children attending the clinic were examined for children with a presenting history of recurrent illness episodes. Generally, this was found in either the general practitioner referral or in the asthma history as recorded at the first visit to the respiratory clinic. Such cases were then approached as per the study protocol. Additionally, colleagues were asked if they knew of any such families. In one case, the asthma specialist nurse had recently visited a family at home to provide an asthma management plan. During the visit, the mother had spoken of a time before the child was diagnosed with asthma when she had been back and forward to the general practitioner trying to get answers about the child's illness. The mother was approached at her next clinic appointment.

Example 2.

Some emergent categories were harder to pursue, such as, for example, if they related to a mothers' practical skills or personally held beliefs. In such cases it was obvious that the researcher would not be able to identify such mothers from the case notes, and, neither was she at liberty to ask mothers such specific

information prior to informed consent. Again, the researcher relied on the insight and knowledge of clinicians within the respiratory team. In particular, close co-operation with the asthma nurse led to a most successful identification process.

A good example of theoretical sampling for this category involved the search for mothers whom staff perceived to exhibit a degree of mastery over their situation. It was quite usual for the asthma nurse to explore such topics with mothers of children during her routine working day, and a number of mothers were identified in this way.

Once alerted to a suitable participant, the researcher would retrieve the child's case notes to confirm that the participant met the full study inclusion criteria. Permission was then sought from the consultant in charge to approach the family. If the child was in hospital at the time, a letter of introduction from the consultant was taken to the mother (e.g. Participant S9). This was followed by a visit the following day and, if the mother agreed, an early appointment for a home visit was arranged. If the child had been discharged or was an outpatient, a letter of introduction from the child's named respiratory consultant was sent to the family inviting them to take part in the study (e.g. Participants S10 and S13). The mother was then contacted by telephone to ascertain whether or not she would like to take part (a few days after the introduction letter had been sent). If she agreed, an appointment for a day, time and location suitable to the mother was arranged. In this situation, there was no personal contact with the mother until visiting the home to conduct the interview. This procedure worked well for the remainder of the study.

Data Collection

The Qualitative Interview

Development of Interview Guide

The primary source of data collection was a semi-structured qualitative interview developed specifically for the study [Appendix 6]. Key references on qualitative interviewing[129-131;136;153], grounded theory[138], explanatory models[154] and patient education[155] informed both its layout and content. It was conceived in a semi-

structured style with sufficient flexibility to respond to important issues raised either by the interviewee or emerging from simultaneous analysis.
From the review of the literature, key principles in the development of the interview guide were distilled and followed. For example, Morse suggests starting with an introductory question that gets the person talking immediately. This may identify issues to return to later in the interview[147]. For the current study, the opening question "When did you first learn that [insert child's name] had asthma?" was composed.

An example of how the opening question worked is given below. The response shows that the mother launched straight into an explanation of her experience. It included issues important to the mother, a long period of frequent episodes of respiratory illness during which the child had symptoms suggestive of asthma, links with other illnesses and myths around diagnostic criteria, including the age at which asthma could be certain and thus diagnosed. These topics recurred throughout the study and became themes that emerged in many interviews and were further developed. The opening question proved so successful in early interviews it was used throughout the study.

Example of opening question:

[Interviewer] When did you first learn [child's name] had asthma?

S1: He had RSV when he was 3 weeks old, and until he was 11 months he had problems with his chest and when he was 11 months old he came in here to have his blood tested to test his immune system. They discovered he had something in his blood that showed he had allergies and it was linked to asthma. They diagnosed him then and there and he was given inhalers.

[Interviewer] Just remind me how old he was then?

S1: He was just 11 months and they just felt no enough is enough from 3 weeks till 11 months he had constant wheezing and coughing. They said it was quite unusual for an 11-month old baby to be diagnosed with asthma but he was so bad he needed his inhalers.

Having identified a good opening question the focus moved to the rest of the interview guide and how it should be constructed. Kvale suggests that interview questions should function on two levels[131]. They should function *thematically* in that they should relate to the topic of the interview, and *dynamically* in terms of contribution to the interpersonal communication within the interview[131].

Thematically, the study was concerned with the emergence of asthma, the development of self-regulation and the interplay with lay health beliefs. Accordingly, relevant literature was examined to explore methods and approaches that others had used which might be considered appropriate to include in the interview guide.

Collectively all of the questions on the interview guide related thematically to the aims of the study. However, to explore specific issues around the emergence of asthma, two questions relating to the onset of asthma and how it might be explained were included:

What do you think caused [insert child's name] asthma in the first place?
Why do you think the asthma started then?

The work of Kleinman[154], discussed in the literature review, was particularly apposite[106;108]. In his book, Kleinman described eight questions that could be used to explore issues around explanatory models[154](page 106).

Kleinman's questions:

1. What do you call your problem – what name does it have?
2. What do you think has caused your problem?
3. Why do you think it started when it did?
4. What does your sickness do to you – How does it work?
5. How severe is it – will it have a long or a short-term impact?
6. What do you fear most about your sickness?
7. What are the chief problems your sickness has caused for you?
8. What kind of treatment do you think you should receive?

The questions relate to key areas of an illness episode; aetiology, time and onset of symptoms, pathophysiology, course of sickness, severity, and treatment[154].

The topics sat well within the frameworks for lay interpretations of health and illness reported in key British studies[98;99;101].

Early versions of the interview guide included the original Kleinman questions, with minor alteration to take account of local variations in language and the fact that the person being studied was the mother of a young child with asthma. For example: Kleinman's original question: *"What do you think has caused your problem?"* was altered to *"What do you think caused your child's asthma?"* Such questions are important to ask as they help explore issues related to disease causality.

One of the study aims was to assess how mothers' beliefs about asthma contrasted with a bio-medical model of asthma. Thus, the first version of the schedule included a question "In your own words, can you tell me how you see the asthma working inside [use child's name]?" Such questions explored the extent of any differences between the lay and biomedical models of asthma.

The first interview response to the question (from participant S1) suggested that mothers might indeed hold a personal image of how asthma worked, which could later be compared with a biomedical model.

> *[Interviewer] In your own words can you tell me how you see the asthma working inside?*
>
> *S1: Right well I would say obviously it's linked to the chest. But I would say it was like narrowing of the airways, which results in a cough and wheeze and if they get narrowed its a wheeze and medication I give well the way I imagine it in my head is I'm giving him medication that's opening up all the tubes and he can breathe better.*

This led the researcher to pursue opportunities in the interview that encouraged participants to describe their personal models of asthma. It was hoped these might include perception of structure of the lungs, disease action and resultant symptoms.

Kvale talks of interview questions working *dynamically*, that is they make a direct contribution to the interpersonal communication within the interview[131]. Thought was given to setting the scene for the interview and flow of the questions. Particular attention was paid to how the interview would commence and what measures could be put in place to put the mother at ease and enhance the communication that followed.

A standard introduction was developed by the researcher to use at the start of the interview. This emphasised that the interviewer wanted to hear what the mother had to say about her child's asthma, or anything that she viewed as important to her about it. It was expected that the content might be emotive, but not particularly sensitive.

The interview introduction:

> "This interview is designed to understand more about asthma from a parents' point of view. I am interested in your own ideas and feelings, and want to hear what you want to say about asthma. There are no right or wrong answers, and all the information you give will be kept safe and made anonymous".

In terms of interview guide layout, Morse suggests grouping together questions concerned with the same topic, and amalgamating any that seem related[130]. A list of 'a priori' questions, which formed the basis of the first interview guide, was developed. At this stage, it was a simple one-sided A4 sheet. As the study progressed in accordance with a grounded theory approach, each interview helped to refine the questions asked, and the wording. Gradually, the areas of focus for the interview guide were refined. For example, early versions of the guide were structured around illness behaviour headings of: disease causality, disease interpretations, and disease longevity. It assumed a formal diagnosis of asthma had been given by a health professional and accepted by the mother.

From early interviews, it became apparent that the mothers recognised a time before the formal doctor-diagnosis of asthma. The mothers described this, as a time when the young child had already started to experience recurrent episodes of what, in retrospect, were asthma-type illness episodes. Despite seeking

medical explanation, the child had not been given a formal medical diagnosis of asthma. As the study progressed, the questions were used to stimulate discussion around emergent themes. For example, in relation to the initial experience of asthma and uncertainty around diagnosis, two questions relating to what was introduced as background information were developed:

1. When were you officially told it was asthma?
2. How was that time for you?

In order to expand the discussion around the development of self-regulation and the emergent themes, more focused questions were included:

1. What have you got to know about your child's asthma over time?
2. How do you know when the asthma is coming on?
3. Faced with asthma what did you decide to do?
4. Can you sum up your approach to your child's asthma?

Finally, interviewer prompts such as "could you go into that in more detail", and "why do you believe that is?" were added onto the guide [Appendix 6].

Setting for the Interview

For qualitative interviewing, Morse suggests the interviewer lets the participant choose where they want to be interviewed[130]. While interviewing participants within their own social context might usually be most appropriate, Morse highlights that this provides opportunities for disruption. In the present study, it was recognised that mothers of young children are very busy and have considerable demands on their time. Their chances of having a quiet hour or two at home uninterrupted were not high. Accordingly, careful thought was given as to how to minimise chances of disruption[130]. As is common practice in interview studies, the mothers were asked to choose where they wished to be interviewed. Eleven chose to be interviewed at home, seven chose the hospital and three requested it be done by telephone. One mother specifically asked to be interviewed in private at her place of work (a hospital). She did not want the child to be present, and did not want to be seen talking about him. The three telephone interviews were included in the analysis on the basis of emerging published support for this approach[129;136;156-158] and an expert opinion sought shortly after

the interviews. A full discussion on telephone interviewing is included later in this chapter.

Field Notes Collection

Additionally, in relation to setting of the interview, field notes were made. Morse describes these as "descriptive accounts in which the observer objectively records what is happening in the setting"[130]. Therefore, whilst the primary fieldwork data collection tool was the qualitative interview, brief descriptive field notes describing the research visit were also completed. In this study, they were used as observations, as a means to capture further information relevant to the participant's environment, and to monitor researcher performance on delivery and success of the interview.

Having completed the interview, and usually immediately on returning to the office, the researcher would jot down any thoughts about how the interview had gone or other material that seemed relevant about the participant or the interviews. Later, when reviewing the interview transcripts, the field notes served as valuable 'aide memoirs' assisting in recalling the mothers and the interview.

A typical example of a field note entry is listed below:

> "S9: White, young Mum, was married now separated and living with her parents and 3 other sibs, plus her own two young children. Living in a working class/becoming privately owned depcat 5 area. Met the mum during a recent hospitalisation of the wee one for acute asthma. Keen to participate and when I rang after discharge we arranged to meet later that week. She was in when I arrived, her youngest (just under 2yrs) was present in the room, but he was lying on couch watching videos. Interview took place in lounge, no smell of smoke but ashtray and lighter on table. Got straight into interview after signing consent, chatted really freely. Appeared quite relaxed, good eye contact. Completed questionnaires afterwards, managed fine, had omitted a couple but I checked and she filled them in then. Her mum and other sibs and her older son arrived midway, they went upstairs, but there were one or two interruptions, just popping head round door etc, harder to keep flow going but did."

The field notes were also helpful to the researcher to record feelings on how the interview went and later for reflection on the interview technique.

Delivery of the interview

The author had worked as a specialist asthma nurse for eight years and had experience at communicating detailed disease information, had regularly used critical asthma communication techniques[57] and was aware of the importance of eliciting the patients' agenda and avoiding a directive approach[159]. Interviewees' perception of the professional identity of the interviewer are known to influence the interview process[160], particularly the type and nature of information that is disclosed. Thus, the researcher had to consider how the mother's perception of whether her professional role, nurse versus researcher, might impact on the interview. The researcher chose to assume the identity of a 'researcher', rather than a 'nurse turned researcher', and all correspondence with the family referred to her as the Asthma Research Fellow.

Whilst there are no absolute interviewer requirements, one can draw guidance from the literature. There is a mass of literature to assist researchers about to embark on their first qualitative interviews. While most qualitative research text books include at least one chapter, some books are dedicated exclusively to the art of interviewing [131]. Kvale suggests the best way to learn how to interview is just to do it:

"*Learning to become an interviewer takes place through interviewing. Reading books may give some guidelines, but practice remains the main road to mastering the craft of interviewing*" – [131] (page 147).

Given the skills required to undertake qualitative interviewing and its complexities, Arskey and Knight suggest even experienced interviewers should perform regular self-evaluation exercises throughout a study. They provide a useful checklist to assist the interviewer to evaluate issues around delivery and data reliability such as whether or not the emergent data answer the research question[129]. The checklist covers issues such as length of interview, understanding of the question posed, whether or not the interviewee talks freely,

and missed opportunities for follow-up questions. In this study, the researcher reviewed each interview using the Arksey checklist [Appendix 7].

Additionally, one supervisor who was experienced in qualitative interviewing reviewed the interview transcripts. At a one-to-one meeting, generally within two weeks of the interview, the conduct and content of the interview was reviewed. The supervisor highlighted areas where the researcher may have over-talked, interrupted, or been too directive. There then followed a discussion on how the techniques could be altered or developed. In addition, useful open-ended prompts were added to the interview guide to act as cues for the researcher during subsequent interviews. This exercise was repeated at regular intervals until student and supervisor were happy with the interviewing.

Establishing rapport

It is recognised that in qualitative studies the quality of data generated is likely to be directly related to the quality of relationship built up between interviewer and interviewee, and the establishment of what is referred to as 'rapport'[129]. Definitions of 'rapport' vary but it is commonly described as the establishment of a situation designed to create a trusting atmosphere in which differences in power, status and knowledge are minimised[129;132]. One factor that can affect rapport is the relative "power" position of the people interacting with one another. Kvale makes the point that a research interview is not a reciprocal interaction between two equal partners[131]. The interviewer defines the situation, introduces the topics of conversations and generally steers the direction of interview. The dilemma for the interviewer lies in achieving a balance between ensuring that the interviewee feels that they are given a genuine opportunity to speak and be heard, while at the same time ensuring that the interview yields information in the area of inquiry.

One potential limitation of the present study was that participants were interviewed only once. Gordon highlights the problems associated with conducting a single interview, and the danger of what he refers to as 'context stripping'[181]. He proposes a three-stage serial interview process. The supposed strengths of the three-stage process are that a developing rapport/relationship allows the participant's account to be put into context. Such advice, which for

many would be impossible within the financial and time constraints of a project, has not been widely adopted. In keeping with this general trend, the present study used a single interview. The principal justification for a single interview was that the study was not investigating issues that were likely to change over a short space of time. The principal problem then arising is the issue of establishing rapport within the time frame of a relatively short single interview contact. Fortunately, a discussion with a parent about a child's asthma is not generally perceived as sensitive. From previous clinical experience working with parents of young children with asthma, the researcher had always found parents were keen to 'talk'. The ultimate test, however, would be what happened in the interviews, and whether or not they were to provide 'rich data'. As such, particular attention was paid to how the 'interview process' progressed throughout the study.

All of the interviews were recorded using a digital Sony Minidisk player. This had several advantages. The equipment was readily available within the department. Secondly, a mini-disk records up to 74 minutes worth at one time. It was expected that most of the interviews would last around 60-75 minutes, so this could easily be accommodated on the disk without need to change. For each interview, a copy of the interview guide was kept at hand. In the early stages of the study, this was used as a guide for the researcher to ensure the key topics were covered. If a mother mentioned something in passing to which the researcher thought it might be important to return, this could be noted on the guide.

Supplementary demographic data collection

Purpose of this information

Additional data were sought about the mothers' in terms of their socio-economic and educational background and their child's asthma history. Residential postcode was used to provide a proxy measure of wealth/deprivation using the Carstairs and Morris deprivation category scores[162;163]. Years of educational attainment reached and employment history provided information on mothers' intellectual capability and level of understanding. The asthma history section provided information on family history of asthma and related atopic illness (eczema, allergies and hay fever) in the child or other immediate family members. A record was made of the child's prescribed asthma medication.

A single A4 page form was developed to collect the supplementary information [Appendix 8]. One form was completed for every participant. The supplementary data were collected directly from the mother, immediately after consent had been gained, and always before the qualitative interview began. The author asked for the information using short, closed questions. The information was not discussed, and generally took no longer than ten minutes to collect. It provided a small window into the 'life and world' of the family, which could be expanded upon in the subsequent qualitative interview. The original form was filed in each individual participants study folder. Anonymised information from the form was also coded and entered in a Minitab[164] database ready for later analysis.

Interview theory into practice

Prior to the current study the researcher had not undertaken any qualitative research. Despite an extensive review of the background theory she was aware that she lacked practical experience in the area. As each interview was performed experience and confidence grew. In addition to using the Arksey[129] checklist for general reflection on interview technique [Appendix 7], the researcher developed a personal guide focusing on putting theory into practice. It was not intended to stilt the interview dynamic, rather it was hoped that it would act as an aide memoir prompting a natural flow. At the time it was developed informally but has been included in the thesis in a structured format as Appendix 9.

Ethics

The study was approved by the Yorkhill NHS Trust Ethics Committee [Appendix 10].

Data Analysis

After the interview, and in preparation for data analysis, the researcher (PM) transcribed the interviews verbatim. This was performed within 48 hours of the interview having taken place. The typed transcripts were anonymised by removal of names and identifiable places, and were allocated a unique study number. The transcripts were also saved as text files for importing into the qualitative analysis package "Atlas" for later data coding and sorting[165]. Atlas, developed by Thomas

Muhr, is a qualitative analysis package, which can deal with large bodies of textual, graphic and audio data. It is based in part on grounded theory and provides the user with a sophisticated tool to manage, extract, compare and explore large amounts of data in a meaningful way. In the present study, much of the data analysis was done using pen and paper with Atlas used primarily for transcript storage, sorting and coding.

The Coding process

Coding is a critical part of grounded theory analysis and is designed to open up inquiry and draw out the categories[139]. Generally, it is described as having three distinct phases; *open coding* - which categorises and opens up the data, *axial coding* - which connects the categories, and *selective coding* - which focuses on the core category[139;166]. In this study, key elements from Grounded Theory coding approach were used to begin to order and drive the development of data coding through analysis.

Coding was first performed manually, and then replicated on Atlas, creating identical paper and computer copies of every coded transcript. For reflecting on text and comparing transcripts, the researcher preferred paper copies. The facilities of Atlas meant that as the number of participants, transcripts, codes and categories increased data were easily stored and retrieved.

Open coding - Getting started

Open coding was performed first. For this, data were scrutinised using a word-by-word/line-by-line approach. Pieces of text and phrases thought to be important were highlighted, and provided with a short descriptive label. The labels were of three types: (i) open; new and created by the coder, e.g. first symptoms/parent labelling/mum diagnosis (ii) a-priori; drawn directly from the research question and interview guide e.g. cause/longevity/beliefs about medication (iii) in vivo; from the interviewee, e.g. neurotic mum/bite the bullet/fast asthma.

In line with a grounded theory approach, open coding and analysis commenced with the first three interviews. Two examples follow of transcription extracts and the open codes applied:

Example 1.

> *S1: "I was told by someone that he probably would have been asthmatic anyway, whether he had RSV or not because his tubes probably were narrower anyway".*
>
> **Coded as**: cause / RSV and asthma / links with other illness

Example 2.

> *S3: "I imagine the severity of it aha, because at times, that's the difference between having a mild bit of breathing difficulty and it being immediately under control by using the reliever to watching it escalate not being under control and thinking okay what do we do next".*
>
> **Coded as:** severity / self-regulatory dialogue / control

Codes to categories – Moving to the next level

The open codes allocated to the three transcripts were examined, and similar codes grouped together. This early grouping of codes suggested preliminary categories around:

- A prolonged pre-diagnosis phase, which was difficult for mothers both emotionally and practically.
- Diagnostic uncertainty
- Suggested causal links with other illnesses
- Hints of a journey of learning to manage asthma, possibly with different key stages, and a sense of an important moment of change
- Lay model of asthma
- Highly developed observational skills

Further interviews were performed, simultaneously exploring the emergent categories, and capturing potential new categories. In time, coding moved from open to axial. That is, as data around a category increased, sub-categories were developed to advance precise explanations of the individual category/phenomenon. As the categories were further refined, coding became selective, with data coded only in relation to the emergent categories. The coding moved from one stage to the next as the theoretical focus sharpened. From early detailed word-by-word open coding, it became focused on the key themes. This process continued until no new information or explanation occurred, a process that Strauss calls "theoretical saturation" [138]. In grounded theory, this continuous

reciprocal process between analysis and interview is known as the 'constant comparative' method.

Simultaneously, the interview guide was refined and sampling became theoretical (as explained in earlier sections). Collectively, this progression from open to selective coding, and the fine-tuning of the interview guide and theoretical sampling, ensured that the emergent themes were explored in detail.

Theoretical memos

Description

Throughout the coding process, the researcher is thinking, reflecting and comparing. In Grounded Theory this action is formalised as memo writing, in which the 'memo' serves as a record of the development of the analytic process, maintaining order of the researcher's thoughts and aiding the search for connections/conditions within categories[138]. Memos vary in type and form, but it is recommended they should be started early in the grounded theory process, should always be written, and should play an important part in the move from data to concept[130].

Type

In this study, two forms of memo were developed: *Individual specific* and *Main*.

> *Individual specific* – related to individual memos that were created on every transcript. Following coding of a transcript, the researcher would reflect on the complete text and how it related to the research questions. Quite naturally, thoughts came to mind and were noted down. Knowing that Strauss advocates adopting reflexive approaches to the data, direct use of his prompt question "what is the main story here?" was employed[139]. A written memo, no longer than two sides of A4, was generated for every transcript (and hence participant) in the study.
>
> *Main* - relates to all other memos created in the study. These most closely resembled the Grounded Theory traditional memo type. They spanned the time covered from early data collection until close of analysis

(approximately June 2002 – June 2005) and charted the development of the data analysis. Frequently, these were no more than thoughts jotted down on A4 pieces of paper. All were retained for reflection as the analysis progressed. Key findings were distilled into a document called 'Themes' which served as a record of analysis progression [Appendix 11]. Printed copies of the document were retained throughout the study and served as the main record of distillation of the analysis

Reliability measures employed during qualitative data processing

Two measures helped to enhance reliability and credibility of the qualitative study findings.

Creating a transparent record of events

Demonstrating a trail of open codes to core categories and themes is recommended to strengthen the reliability of findings[151]. In this study, two written records were developed to document activity around qualitative data processing and analysis; (i) Analysis Audit Trail [Appendix 12] and (ii) a document titled 'Themes' [Appendix 11]. The Analysis Audit Trail was used to record progress and study development. The document 'Themes' emerged as a method to summarise coding progress for the regular supervisory meetings.

Inter-rater reliability checking

A supervisor (K. Mullen) experienced in qualitative research closely monitored data collection, coding and analysis. A written record of everything that was performed was retained. He and the researcher met at regular intervals to assess and discuss progress.

It was agreed that the researcher would carry out three interviews, transcribe and open-code the transcripts then meet with the supervisor to review the work. As discussed earlier, this doubled up to serve as an exercise to assess the researcher's progress in the qualitative interview technique. At this early stage, the supervisor was satisfied with what had been completed. A simple open-coding summary and sampling trail was created.

The researcher carried out seven further interviews. These were coded as before. From the ten completed interviews, three (S5, S11 and S12) were randomly selected for further scrutiny. Blank, as in un-coded, original copies of the transcript were sent to the supervisor for him to perform open coding. The two then met to review and compare the supervisor-coded transcripts with the researcher-coded transcripts, looking particularly for areas of divergence and agreement, and to review the coding summary. There was general agreement between the two, although the supervisor had also identified a possible coding category 'stigma' that the researcher had not. For a short time, sampling pursued the "stigma" category but it led nowhere new. It seemed to be specific to 'young single mums' and, as the study was not investigating stigma, it was not pursued.

In order to perform a further check for consistency of coding and the building up of the results, the following was arranged. As the coding summary grew and became more focused, it became a document called 'Themes' [Appendix 11]. Essentially, this document collected a record of how the key themes emerged from the data and detailed their construction. As the theoretical sampling progressed, the researcher updated the document after each interview, filling in more and more detail on the emerging themes. The document was then sent to the supervisor along with copies of ten further interviews. Following this review, the supervisor confirmed that analysis was progressing adequately.

Additionally, all transcripts and the coding summary document [Appendix 11] were reviewed at regular intervals by all three supervisors. The data, the emergent analytic categories, interpretations and conclusions were discussed with the three supervisors during regular review meetings.

Interviewer objectivity

When using grounded theory techniques researchers are asked to put aside their personal knowledge of a subject in order to allow the new interpretations to flow from the analysis[138]. Strauss described this as:

"In qualitative research, objectivity does not mean controlling the variables. It means openness, a willingness to listen and give voice to respondents. It means

hearing what others have to say, seeing what others do, and representing these as accurately as possible" [138] [page 43].

Adopting such a stance may be particularly difficult for qualitative researchers studying within their own expert field. Indeed, Strauss recognises that complete objectivity is unattainable, and that all individuals will approach study with a degree of personal knowledge and experience. Instead he suggests researchers consider adopting measures to stimulate thinking about common dimensions within the data rather than allowing personal knowledge to direct analysis per se.

The researcher, as noted previously, was an experienced paediatric asthma nurse with a background in health service research and an interest in family management of asthma. Therefore measures to allow her to gain both distance from the emerging analysis and reduce any preconceived analytic bias were seen as important.

The following measures were employed:

Firstly, further exposure to the literature directly corresponding to the focus of the current study, namely self-regulation and lay health beliefs, was limited to that deemed necessary to inform the qualitative methodology. For example the wider literature on lay health beliefs was not reviewed prior to the qualitative analysis. Only when analysis had generated a mothers' lay model of asthma was it contrasted with published accounts of lay models.

As stated previously the original intention of the researcher was to conduct an intervention study designed to enhance self-regulation in mothers of children with asthma, not to undertake a qualitative study. Thus, by the start of the qualitative study she had already had considerable contact with the quantitative measure of self-regulation described by Zimmerman et al[85]. To counter this it was decided that throughout the data coding process no descriptive labels relating explicitly to the Zimmerman four-phase model would be used. Additionally, throughout the analysis process the researcher adopted a reflective approach of saying to herself "What are the participants saying?" not "What am I hearing?". It was hoped that exercising such restraint would allow a degree of neutral distance to

be achieved. Finally, data collected from the questionnaire assessment of illness perception and disease management behaviours were put aside for comparison until after the interview data analysis was completed.

Telephone Interviewing

As stated previously in 'Setting for the interview' section, three mothers (participants S6, S8 and S12) when approached to take part in the study specifically asked for their interview to be conducted by telephone. At this stage it was not clear whether this would be appropriate or not. In practical terms, it was feasible as a speakerphone was available for use. Additionally the minidisk microphone was sensitive enough to record the interview directly from the phone. Whilst realising that mixing methodology was not recommended, the researcher felt keenly that the mothers' request should be honoured. Although not experienced in telephone interviewing, the researcher had through her previous clinical experience as the Asthma Nurse run a successful asthma helpline and was used to discussing 'asthma' with parents over the phone. She was confident that she could conduct the interview using this communication medium. Therefore, the researcher proceeded with the three telephone interviews and included them in the study.

The three participants were all identified using the 'in advance' sampling technique as described earlier. That is, they had been identified as potential participants before they attended with their child at the clinic, and had been sent the study introductory letter prior to the appointment. They had agreed to participate when asked at the close of their child's appointment, and gave written consent in exactly the same manner as the other participants. When asked when and where they wanted their interview to take place they asked if it could be done by telephone. Having agreed to do so, the mothers and the researcher then arranged a suitable time for the call. On the agreed day, the researcher phoned the mother as requested. For participants S6 and S8, the interview proceeded as arranged. When the researcher phoned the home of participant S12, her husband answered and informed her that his wife had a migraine and could not come to the telephone that day. Instead, the mother had proposed an alternative time and day the next week. This was agreed, and when the researcher

telephoned the following week, the mother was fully recovered and the interview progressed as planned.

At this stage, an expert opinion was sought on whether or not it would be appropriate to include the telephone interviews in the study and, a review of the literature on telephone interviewing was undertaken. Professor Margaret Reid, Professor of Women's Health, at the University of Glasgow, was approached by the researcher and asked for her opinion. Professor Reid is a prolific qualitative researcher, with an excellent track record, and she teaches on the qualitative research module of the Masters of Public Health course.

As the number of parents who requested a telephone interview was so small (3/21), Professor Reid agreed that denying them this facility when they had specifically requested it, would exclude a group who might have unique characteristics relevant to the overall context of the study. For example, this group of parents may express this preference through a desire for control, or convenience. Additionally, excluding the three participants would have slightly reduced the overall study numbers.

The use of telephone interview for research

As stated, a review of the literature on the use of telephone interviewing was performed following the three telephone interviews. A summary follows.

Whilst telephone interviews are synonymous with large scale surveys[129;131], Robson suggests they may have a wider application as they share many of the advantages of face-to-face interviewing; namely a high response rate, easy correction of obvious misunderstanding and possible use of probes[136]. Whilst claims that it can be used as a validated qualitative tool have been questioned, it has not been eliminated as an idea for future investigation, particularly in nursing research[156]. Lack of visual clues, difficulty in establishing rapport, and an assumption that the interviewee will not disclose important information appear to be the main criticisms.

There is a small number of reports in the literature supporting further exploration of qualitative telephone interviewing (QTI) as a research tool in health

research[156;157;167;168]. These come largely from the nursing research area, and do not appear yet to have encouraged use of the technique within the wider social sciences. Within this small body of literature, QTI has been used in smaller sub-samples within larger quantitative studies[168] where the target population is geographically widespread[156;167], or for convenience[157].

Studies using qualitative telephone interviewing for research

In a subset of 24 parents taking part in a larger quantitative study, Ainbinder et al examined qualitatively the experience of parents participating in a parent-to-parent support programme in the USA[168]. The parents, all who had a child with special needs, participated in a semi-structured interview designed to explore the impact and meaning of being paired with a trained support parent. There was no face-to-face contact or recruitment by the researcher conducting the interviews. Instead, families were invited to take part by letter by the lead researcher. They were told that if they agreed to participate, they would be telephoned at a later date by another researcher experienced in psychological research. Of 38 parents approached, a random sample of the larger quantitative study group, 24 agreed and returned a signed consent by mail. QTI was selected for convenience and because the sample was geographically widespread. The authors quote the work of Miller finding that telephone interviews, while of shorter duration, usually yield similar levels of disclosure compared to face-to-face method. One initial contact was made to the family by the interviewer in advance of the QTI to set the agreed date. All interviews were semi-structured following a standardized topic guide. The duration of interviews showed a degree of variation, ranging from 15-45 minutes. Duration appears to have been related to the experience of the parent being interviewed, in that those who had a positive experience with a support parent generally engaged to a greater depth in the interview. The transcripts were recorded, fully transcribed and analysed following constant-comparative procedures. The study appears to have been successfully executed.

In Australia, Sweet used telephone interviewing in her phenomenological study exploring parental breastfeeding experiences in pre-term infants[167]. She used it as a supplementary method to face-to-face interviews for retaining families who lived a greater distance away from the study centre. Consideration of the technique arose in response from a father in the study who wished to participate

further but would not be in the near vicinity at the proposed time. For those families with whom the follow-up interview was conducted by telephone, the author states that the nature and content of the interview seemed no different. Key points that might have contributed to the success of the approach included: face-to-face recruitment so that the 'rapport' or 'research bond' had already been established; parents seemed comfortable with it. In that study, data from the telephone interviews were combined with data from face-to-face interviews for analysis. The author states that there was no difference in length of interview or narrative detail between the two methods, and that neither was easy to distinguish from the transcripts. There was no other formal evaluation of the data collected from the two different approaches.

In her doctoral study, Carr explored the impact of pain on patient outcomes following major surgery[157]. The main study group (N=85) completed quantitative questionnaires assessing level of pain, anxiety and depression. To gain a qualitative insight into the topic, a smaller sub-group of 37 patients were selected for additional semi-structured interview by telephone. The method was chosen primarily for convenience, as it was not possible for the investigator to travel to the patients' homes to interview them in person. It was also based on Carr's previous experience where the earlier use of face-to-face interviews conducted in hospital during the post-operative period had not yielded the richness and depth of data expected. All of the interviews were recorded and fully transcribed, and took place between set time margins which had been arranged in advance to avoid conflicts with mealtimes and other family activities. None of the participants refused to participate. The previous face-to-face contact had established good rapport and the patients seemed pleased to have an opportunity to discuss their recent experience. The author admits there were some occasions when conversation dried up and the interviewer, without visual cues, was unable to interject in the same way as one would in a face-to-face situation, so that important data may have been lost. However, they also suggest these 'natural pauses' were more easily tolerated by telephone, and often did allow for the respondents to take time to think over and respond. This suggests pauses on the telephone may be less socially awkward, and even better tolerated.

Chapple describes a study exploring women's perception of vaginal thrush[156]. The women were identified whilst purchasing over-the-counter treatments for thrush in community pharmacies across England. The women were recruited on site by the Pharmacists and invited to complete a questionnaire and consent for a telephone interview at a later date. The telephone interview was chosen specifically as the study covered a large geographical area of England. Chapple was responsible for conducting the interviews, despite not having been present during the face-to-face recruitment. She openly acknowledges the difficulties this could have created, but as an experienced post-doctoral researcher with an interest in women's health, she agreed to conduct the interviews.

In order to gain the women's trust and confidence during the interviews, she adopted the following approach.

- Providing an initial introduction, stating clearly her name and place of work,
- Disclosing that she herself had experienced a similar event (she had encountered thrush and had tried non-pharmacological remedies)
- Revealing her nursing background.

What is interesting in this account is that the topic, by nature sensitive, could have caused the women a great deal of embarrassment. In contrast, Chapple questioned whether the women's dialogues would have turned out to be quite so revealing had she been sitting in the same room as them. Thus, in retrospect, the technique (QTI) that was initially selected as a convenient way to follow-up a geographically spread sample, proved to be extremely useful.

Throughout the article, Chapple provides a series of practical pointers: covering introductory dialogue, appropriate technology, timing, organisation and confidentiality, for any researcher about to embark on QTi. She discusses the importance of responding to aural rather than visual cues, and being sensitive to periods of silence and responding to tone of voice. By sounding interested and concerned, and using personal experiences, she was able to encourage the women to talk.

Conclusions from studies

Much has been written on the skills required for face-to-face interviewing. It would seem from Chapple's accounts that the QTI also requires a set of specific skills even though they may be slightly different. It may not be coincidence that the supporting literature in this area comes from the discipline of nursing; an area where high quality communication and interpersonal skills are critical.

Whilst the first line approach of the current study was to conduct face-to-face interviews, it was felt that there was enough support in the literature to warrant the inclusion of the three telephone interviews undertaken at the parents' request. Additionally, the telephone interviews did not differ significantly in length or in content from the other eighteen interviews and were thus included. The median length of interview for the full twenty-one participants was 68 minutes (Range 34-75 minutes). For the three participants interviewed by phone the median length of interview was 46 minutes (Range 38-72). Overall, the shortest interview recorded in the study was with participantS2, conducted face-to-face, which lasted 34 minutes. As the qualitative analysis progressed, there were no obvious differences in the quality or content of the telephone interviews or signs that the three mothers held different beliefs or characteristics. Finally, it is worth noting that when a supervisor, K. Mullen, reviewed a group of transcripts, which included the three telephone interviews, he was unable to distinguish which was which.

Conclusion

In summary, this chapter has described in detail the qualitative methodology underpinning the study. The next chapter presents the first of the qualitative interview results.

CHAPTER 4. SEEING THINGS

In the beginning...

Childhood asthma commonly develops early in life, often before the age of five[19].

All the children in this study were reported by their mothers to have experienced symptoms of asthma before their third birthday; most (17/21) had symptoms within the first twelve months of life. All the transcripts included descriptions of symptoms such as recurrent respiratory illness episodes, constant runny noses or recurrent colds, which are commonly described in young children with asthma.

Regardless of when asthma symptoms first presented, in each and every child the mothers had quickly spotted they were present. This suggested that the mothers quickly became alert to the signs of illness in their children. They appeared to have a 'seeing skill' - a sense of expectant watchfulness that quickly identified the early signs of asthma. As the data collection progressed, it appeared that this watchfulness pervaded all the mother's experience of asthma in her child. For example, it was seen at the time when the child was first developing symptoms of asthma, and it was still present later in the course of the illness when the observing of asthma symptoms was used as a prelude for action with the administration of treatment.

This chapter discusses this skill and how it was used in practice.

Emergence of the theme

As noted in the previous chapter (Methodology; Strengthening Qualitative Studies section), a deliberate decision was made in this thesis to exhibit a high degree of transparency around how early classifications and themes emerged from the data. Therefore, this chapter commences with such description.

In the first interview with participantS1 it was noted that the mother described skills around early observation of the onset of an acute asthma episode.

> *S1: "I can tell before his cough even starts that he's going to have an attack, I can tell by his colour, I can tell by his eyes, his eyes go really dark*

underneath, his hands go cold and he has terrible mood swings, starts crying at the slightest wee thing. I can tell right away".

At this early stage, no changes were made to the interview guide, but the interviewer was sensitised to observational skills as a potentially important finding when conducting the second and subsequent interviews.

Skills of observation also emerged during the second interview where the mother described herself 'watching' the child. Again, this was directed watching in the sense of noting an early sign of asthma and being observant about how it developed. She could then proceed with the asthma medication. The quote follows below.

S2: "Usually her asthma starts with a cough so I know I just keep her in the house I won't take her out and I'll just watch her and usually I need to bring her in… you know I'll multi-dose her and if she doesn't get better."

By the third interview it was clear that evidence of observation was easily recognisable in the transcripts through the use of words such as "looking", "seeing", "alert to", and "constantly watching". At this stage, it was noted that what was being described was observation in the context of a medical diagnosis of asthma and often in relation to treatment of asthma.

It was in the fourth interview that the possibility of the observational skill pre-dating a diagnosis of asthma was raised. In this context observation was used to see asthma develop in the child in the first place. When responding to the question early in the interview, "When did you first learn he had asthma?" the mother (Participant S4) described her son's recurring cough. She then recounted a conversation she had with her mother who had also noticed the cough. Because of this, the mother was prompted to take the boy to the general practitioner, where he was given a diagnosis of asthma. The quote follows:

S4: "when he was very young from about 6 months old when he had this funny kind of dry cough particularly when he exercised in his baby gym and things like that he hadn't had any cold or anything but seemed to get this cough whenever he took vigorous exercise and it was actually my mum who said to us have you ever asked about that wee cough that he has and we said no do you think its anything and she said it just seems like a big

cough for a wee baby maybe you should ask about it. So we asked our GP who said it sounds quite likely that he may have asthma".

Thus far into the qualitative study it was possible that the mothers' seeing skill could be used for:

a) Seeing signs of asthma developing in the child
b) Early recognition of an asthma episode coming on
c) Seeing as a precursor for therapeutic intervention

a) Seeing signs of asthma developing

Different from normal

As described above participantS4 had noticed the development of chronic cough in her son. She, and her mother (the boy's grandmother), had observed the intrusion of cough into his normal day. This was also suggested in the next two interviews in which both of the mothers described a growing awareness that their child was 'different' in some way.

In the interview with participant S5, the mother described observing differences between her two sons, one of whom, had asthma whilst the other did not. How she described this follows:

S5: They are very physically different children by far, he has his dad's frame and my other son has my frame and [the boy with asthma] was quite a poorly sickly child, not unwell all the time but compared to some other children he was whereas my other son is never ever been really unwell… He [the boy with asthma] was very young as in 6 months to 18 months he had very bad sickness, constant runny noses, as in lots of mucous he was always lethargic and never just his best.

The mother next interviewed (S6) also described how she noticed that her child was different from her sister's child. By chance, the mother and her sister had both been pregnant at the same time, allowing for a direct comparison. Her nephew, the boy without asthma, was never ill, whereas her child often was.

S6: "The reason I know it is my sister and I were pregnant at the same time

and her wee boy sailed through never had anything and I was always in and out with him [to the GP] at first I put it down to I was just an over anxious mother but it just got part of the course with him then".

As more interviews were conducted further evidence that the mothers clearly spotted changes in their child with the onset of asthma emerged with some common themes noted in the interviews.

The mothers described seeing recurrent illness episodes.

S15: "First time she ever got the shortness of breath she was 10 months old and it continued quite regularly over the next year or so"

The mothers clearly spotted that something was wrong; children were described as being repeatedly unwell with symptoms that were related to the respiratory system.

b) Early recognition of acute episodes

The early interviews had illustrated that the mothers were able to link particular signs to an acute asthma episode coming on (participant S1 noted darkness around the boy's eyes and participant S2 described the start of a cough). By the fifth interview, a clear picture was emerging of a group of mothers who were experienced in observation.

Observation became a dominant activity and key in the mothers' management of the child. Some mothers implied it was a full-time occupation. Participant S4 likened this to being in a state of constant alertness: "on our toes looking out" was how she put it.

S4: "We have to be on our toes looking out for symptoms developing and I suppose when he starts to get a runny nose I'm already thinking there's a virus in his airway lining I wonder if this is the one that's going to start to trigger and irritate his airway I don't know why some do and some don't but the minute he starts to get a snuffly nose we start to become alert"

This idea of always being alert was confirmed by participant S5, who talked of "constantly watching". What were they looking for? From the transcripts, the

evidence was that that they were watching for signs of asthma coming on in order that they might intervene to prevent it worsening.

The mothers were clearly skilled at identifying early signs of an imminent asthma exacerbation. Participant S9 described this as "learning to spot the signs". The following examples illustrate the sort of signs the mothers described. Interestingly, in both examples the mothers do not use signs from the respiratory system but made use of non-respiratory clues.

> *S9: "I just know by looking at him, he gets these dark rings at his eyes, and a really runny nose, and a bit grumpy… I know when I see them I starts the multi-dosing".*

> *S12: "He gets dark about the eyes, but I don't look and go oh you've got dark rings under your eyes. He gets dark and in my mind I know he gets tired but it's no tired because he hasn't been to bed. It's just something different. I just know".*

Other non-respiratory signs included changes in behaviour:

> *S8: "His eyes are awful underneath quite dark and he's quite stroppy".*

> And again:
> *S18: "You see her behaviour going down and you know she's gonnie have a wee attack she's gonnie go downhill".*

The mothers' observations are typical of asthma attacks in children and are important features used in developing treatment plans. Most exacerbations of asthma in children develop over a period of days and are commonly triggered by viral upper respiratory tract infections[169]. Non-respiratory signs and symptoms often precede asthma attacks in children. Signs such as stroking the chin and/or throat, behaviour change and dark circles around the eyes are commonly reported. Whilst the patterns of symptoms may vary between children, the pattern of symptoms and their evolution tends to be consistent within a single child[169]. This means the early signs in a particular child tend to follow a similar pattern with each asthma exacerbation.

Some mother's described more unexpected early signs seen in their children. The following mother described a 'smell' that she associated with the start of her son's asthma episodes.

> *S7: "I'll take him to the doctors and they'll say to me they can't find anything yet I know its there, and there's a smell off his breath, don't ask me what that is but I've said it to people before with asthma, I've said it at the hospital, he has a certain smell and I know he's unwell".*

Three further mothers included an unusual smell as an important early sign linked with the onset of an acute asthma episode, which suggested that there might be a wider variety of non-respiratory early signs than initially anticipated. The smell as an early sign is an example of an observation that is currently beyond medical knowledge. Yet it is now known that the inflammatory process occurring in the bronchial epithelium in asthma gives rise to volatile products in the exhaled air such as nitric oxide – which can be detected and measured in the exhaled breath[170-172]. It is highly likely that there is a change in exhaled products during an attack, and the smell the mothers described may reflect an exhaled volatile component linked to the inflammation in the airways. By the end of the study, five mothers, (S7, S9, S11, S13, and S21) had reported this unusual sign. It is noteworthy that these mothers had given descriptions containing detailed observations that could not have been anticipated or learned from current medical knowledge.

Thus the mothers had often very detailed information to give about how they recognised asthma attacks coming on in their children.

c) 'Seeing' as a precursor for action

Over time, the mother's observation of their children became combined with therapeutic actions. For example, observation of acute symptoms developing in the child was then associated with the administration of inhaled medicines for asthma. In this age group of children, spotting early signs of asthma would be particularly important because young children do not have language skills to be able to describe accurately how they are feeling.

An excellent example of how this was used in practice was seen in the interview with participant S15. She first described starting home treatment when she recognised that the acute sign of wheezing presented.

> *S15: "So the first bit of wheezing I would be getting her to use her blue inhaler and I'd maybe be doing that if she was a wee bit wheezy maybe just in the morning what can happen is I can do that and think right a couple of puffs of ventolin or more than that if she needs more".*

The interview developed with the mother describing what she did next and how she judged how much medication to give, and assessed whether the treatment had worked or not.

The mother described first gauging the severity of the impending episode by the presence, or not, of other signs. The mother adds in coughing and being "crackly". That is, if the child develops a cough, a wheeze and starts to sound "crackly" this is used by the mother as a sign that the asthma is progressing to a more serious level. Thus she seemed to have developed a method of assessing severity of the episode. The presence of all 'three' indicated that an episode needed a strong response. In the following extract from the interview, the mother described the methods that she used for gauging success of treatment, or "sussing out" as she called it. Her main markers for efficacy of treatment, in her own words, were: "playing, eating and energy levels". Through observation of these markers the mother could determine whether the treatment she had started was being effective:

> *S15: "Well if she was quite, well say like just now she was coughing so I'm just kind of giving her a couple of puffs, the blue puffs in morning and at night well before she goes to bed eh if she was still coughing a lot or is she started to get sound crackly as well as wheezy, you know that way, I would give more kind of thing but if I'd given two puffs and she was still playing an drinking jumping up and down having her tantrums whatever she's doing and as normal and not seeming particularly sleepy you know lethargic or anything I would be happy with that its where I suppose with her you notice it because she maybe won't eat anything where normally she would or maybe she be a bit more lethargic and we can be a bit of an out and about…if she's okay with it anyway she'll get on with her playing, so it would*

be about playing and eating, her energy levels I would suss out through that".

The next stage for this mother involved deciding on the number of puffs of reliever treatment that she would give, and what she would do if the home treatment failed:

Interviewer: "If you gave the blue and you didn't see an improvement what is your plan to do next?"

S15: "I would up the dose of blue and I would try it every 4 hours so I would go into multi-dosing every 4 hours so I'd maybe try that for a wee while but I wouldn't if she was at that level where she's gone really far downhill I would just go back up to doctors if she was bad but not quite there I would multi-dose every 4 hours".

This example illustrated a number of important points. It is clear that the mother had developed skills of observation, and then used her observations as a basis to guide her actions.

Other mothers described methods of assessment similar to those used in hospital.

By the end of the study, it was clear the mothers had developed a range of signs and symptoms they could observe when their child became unwell. These commonly included:

- Breathing pattern – this included the rate of breathing and whether it was faster than normal as well as effort of breathing. If the accessory muscles such as abdominal were being used this was taken as a sign of a more serious situation. This was usually referred to as: "tummy" or "belly" going up and down really fast.
- The child's general colour. Any tendency toward a paler colour than usual was noted; "When she falls sick she goes very, very pale". Colour returning to normal signified the start of recovery; "You can see the colour coming back into her and you know she's picking up again".

- The child's general mood or demeanour, and any evidence of a worse mood than usual was noted as significant; "He's not gurny then I say he is getting better".
- The child's appetite. This would decrease with the onset of an acute episode and increase as recovery came. Recovering the appetite was seen as a sign that recovery was starting; "His appetite picking up"
- The child's activity or energy levels. As the asthma increased, the child's willingness or ability to be active and play was decreased. As the episode subsided, the child regained usual energy levels; S6: "I can tell if he's getting better just from the way he's breathing and then if he starts to get a wee bit more energy in him".

Collectively, the mothers' used the measures as a means for seeing whether or not the child had recovered.

The question arises as to how the mothers had developed these skills? Were they spontaneously developed and natural to the mothers or had they been learned from the health professionals? Evidence from the transcripts suggested that in the main, these skills had been influenced through repeated contact with health professionals.

There was also the question of what the mothers called "intuition". In this situation, one gained a sense from the interviews that some of the activity was simply what a mother did, irrespective of whether or not the child had asthma.

S12: "I can spot the signs, I don't know if you call it intuition... I just know"

Another mother implied that a mother's role and skill operated on a higher level than that of a health professional. She had been explaining to the interviewer about what it was like being in hospital. She gave a sense that she saw nurse-monitoring skills as different and somewhat inferior from her own. She did not imply that she saw the nurse as being more knowledgeable than herself.

S9: "I stay in with him and I do everything. They do their things, like the 'sats' (oxygen saturation monitoring) and well... anyone could do that".

Most mothers described having learnt some of this from a specific health professional, where the purpose of the session had clearly been to pass

information of importance on to the mother. Participant S4 gave two examples of how this had occurred for her. The first doctor she mentioned was working in the out-of-hours emergency medical service that she had attended with her son.

> *S4: "we'd given him loads [of Ventolin] and gone to GEMS It's the usual thing out of hours the doctor said I think he really needs to go to the hospital she showed us his ribs moving in and out she said that's accessory breathing looks to me like he's struggling a bit go up to the hospital so we went up and they gave him nebulised salbutamol and he stabilised and everything was fine."*

Later, she described a similar episode of being passed information from the asthma consultant at the hospital clinic. This was in a non-acute situation and was discussed in relation to the development of an asthma plan for the child.

> *S4:" [The consultant] asked us what sort of thing we had noticed so I said his ribs going in and out was really obvious so he wrote that down on the asthma plan as signs to look out for. He started off with easy signs like runny nose, cough that sort of thing so up the regular medication the next thing much more serious signs would be when to get extra help you can see his ribs moving in and out that type of thing so we talked a lot about symptoms that he had that we noticed. The doctor wrote that into the plan and said this is just the start of the asthma your job is to go away look and observe see if this is right tweak it and modify it and phone me if it's not right and so the plan was slightly modified over time".*

Further examples of the mothers developing their observing skills with input from a health professional were seen. These all focused on breathing, that is the effort of breathing that the child was making and the rate of breathing, the faster and more number of breaths per minute, then the more severe the episode was likely to be.

> *S17 "[the consultant] has told me that if I check 40, [breaths per minute], over 40 that's definitely asthma because sometimes I was checking him and he was maybe 25 but I thought is that asthma but now I know its not its but if he was breathing over 40 I would and it wasn't getting any better I would definitely take him to the hospital".*

Two mothers had also devised their own scales.

> *S5: "When we can pick up that he is coughing a bit say at stage 1 or 2 on a scale of 1-5 say he's at 1 or 2 with a bit of a cold he's beginning starting cough it might not be at multi-dose stage yet but what we tend to do is we rather than take them swimming, rather than let him go to his dancing class we'll change our plans, we won't stay in, we won't cook him up but we'll stick him in the pram with his wee brother, wrap him up well make sure he gets a bit of fresh air and just go a walk, and then come home and let him chill out and sometimes you can see that lets letting his system whatever it may be give him a bit of strength and so forth.*

The interviewer than asked "What would you do if it was a 5?"

> *S5: Go to the hospital. Initially I would multi-dose, I think you're only supposed to multi-dose every 4 hours, but I'd multi dose and if I felt I'd do it every 2 hours and if I wasn't getting any joy there I'd go to the hospital.*

Participant S9 had also devised her own 'home scale'. She used one based around three stages with the third being very bad.

> *S9: I've got this thing like I have three stages, okay, middle and last. Like okay is now usual thing, middle is when he gets bad, like the wheezing and we start all the treatment, and the last stage I've never seen it but I can imagine what its like in my head like he's there fighting for breath and I just never want to let it get there. So I see my three stages, and I do everything to keep from that last stage.*

The observational abilities that all the mothers described were impressive. With increasing experience, their watchfulness developed to a level where they were alert to small differences in their child's illness. Sometimes they commented that a usual marker of improvement after treatment was not evident, or that a specific symptom occurred that had not been evident in previous episodes.

Participant S16 described an episode in which she demonstrated a further advanced level. She described an asthma episode that she had treated at home.

Two unusual things occurred. Firstly she saw that her child had not responded as usual and she noticed an unusual asthma symptom.

> *S16: "I had noticed then that multi-dosing him and giving him the steroids wasn't making an improvement he was still coughing he was coughing up phlegm which he doesn'y usually do if its an asthma attack, but he was coughing up green phlegm I was like well usually green phlegm is an infection from the lungs and I'd explained all this to the doctor as well I actually said to he I'm convinced you've got me down as some sort of neurotic mother I says but I'm convinced he's got a chest infection I says you're the doctor but I'm his mother and instinct is telling me this isn'y asthma, he's got a chest infection".*

Discussion

Vigilance

An emerging theme from a careful review of the transcripts is one of the mothers being persistently alert or watchful of their child as he/she experiences recurrent respiratory symptoms. There was a clear sense that this watchfulness becomes more structured and developed over time. The mothers started to develop clear illness pattern recognition and they could highlight points when the usual illness script in their child was not being repeated accurately. They also started to be able to use the recognition of early illness signs and symptoms to trigger starting early treatment.

The heightened state of watchfulness that the mothers described might be referred to as a state of "vigilance". The mothers generally described such watchfulness as just 'something a mother did'. In this sense, mothers might be considered as skilled, natural observers. Indeed, observing one's child would be commonly regarded as an essential parenting skill. Thus, when signs and symptoms of asthma arrived in their homes, they were spotted swiftly. What was rather striking about the mothers' vigilance in this study was the fact that they focused on issues of medical importance. In part, this may be related to the fact that this was a group of experienced mothers who attended a specialist paediatric centre. However, with the amount of information that must have been available to them, they had filtered out information on things that were important for them to

see and act on in relation to their own circumstances. Whilst the mothers often used lay terms to describe their actions, the measures that they focused upon when assessing the need for action, map closely onto those recommended by health professionals for the assessing the severity of asthma episodes such as degree of breathlessness, use of accessory muscles and breathing rate[21;23]. However, the fact that some of the observations were beyond current medical understanding argues for the fact that it was not all a consequence of information that might have come to them through their medical contacts. Indeed, in the case of those mothers identifying smell, many doctors might easily have dismissed the information out of hand, as not a feature of asthma.

Vigilance in health

Vigilance in health is not a new phenomenon and has been reported in relation to self-care and in care giving to others. It was noted by Orem[173] to be an essential ingredient for adults with chronic illness, and may play an important role in helping to gain a sense of normality in an ever-changing, unstable threatening situation. For example, Meyer describes a four-part process of vigilance used in female adult migraine sufferers. Migraine, like asthma, is a naturally fluctuating disease that can be precipitated by exposure to certain triggers. The women in Meyer's study used vigilance in their struggle to maintain a sense of function and normality[174]. She described the process as comprising of four elements; watching out, assigning meaning, calculating the risk and staying ready. Collectively through vigilance the women were able to regain control of their life.

Vigilance in parents of children with health needs

Vigilance may be particularly important in asthma because of its nature as an unpredictable, fluctuating disease. In this sense, asthma might be thought to differ from other chronic diseases such as diabetes and cystic fibrosis, which have more constant symptoms that require daily attention. Yet the evidence suggests this is not so. Vigilance has been seen to emerge as an important theme across a spectrum of studies of parents caring for ill children[175-178]. For example, in a study of mothers of young children with newly diagnosed diabetes mothers reported vigilance as their dominant management behaviour[175]. Like asthma, diabetes presents a unique set of difficulties for parents during the

toddler and pre-school years. The children do not always cooperate with administration of treatment or regular food regimes, and cannot clearly express signs of an impending hypoglycaemic episode. In Sullivan-Bolyai's study the mothers described how they used "constant vigilance" as an overall means for managing on a day-to-day basis[175]. As in the current study vigilance was not simply a single activity, rather it was multi-purpose, was used in different situations and often prefigured action. Through the deployment and development of vigilance the mothers learnt to monitor the child's daily state, react to sudden changes and eventually to intervene in order to maintain a desired state of equilibrium. As in the current study, the mothers learnt to interpret a variety of early (behavioural) indicators of a hypoglycaemic episode and by acting swiftly and appropriately, avert a diabetes crisis. This theme of maintaining stability through constant vigilance and intervening early to avert a serious health-related problem has also been reported in families of technology dependent children[178].

At the other extreme of childhood care vigilance has also been described as having a role in establishing a sense of normality within the family when confronted by illness challenge[176;177]. May describes how mothers of low birth weight infants used it in their search for normalcy[176]. Burke et al. noted in their grounded theory study of mothers caring for chronically ill children that developing vigilance was one way of taking charge of the situation[177]. In Burke's study, vigilance was expressed as being there, ready, just in case. All of these studies show commonalities across the challenges that confront parents and how they deal with them.

The current study tells something about the situations through which mothers developed and used vigilance. It was seen to have a role in three situations in the asthma setting: firstly, in relation to seeing asthma develop in the child, perhaps representing the start of skill enhancement; secondly, it was used to detect early signs of asthma episodes; and finally, it was used as a precursor to action, where it was used most powerfully as a way for the mothers to alter or gain control of events surrounding their child's state. Through development of vigilance the mothers remained dominant, active forces in their child's care.

Vigilance in self-regulation

Observation is an important component of the self-regulation model of behaviour proposed by Bandura[71;81] [Figure 1]. In this theory, as described in the introduction, self-regulation operates through three sub-processes: observation, judgement and reaction. He proposes that people cannot influence their actions if they are unaware of them[71]. In this formulation, self-observation provides essential information that is used for setting standards and evaluating changes in behaviour. Thus, observation is a critical component of the self-regulatory model[179]. The mothers provided excellent examples of how they used watching to determine actions. Such a cycle maps closely with the self-regulation model and demonstrates how an observation can be used to trigger thought or action. However, within this theoretical framework, the natural observation skills that the mothers display are of great interest. They clearly equip these parents well for the potential development of self-regulatory skills.

Vigilance as part of asthma care

Routinely looking for early signs of an asthma attack has been identified as an important component of self-regulatory observation[67]. Parents have been shown to be both capable and skilled at spotting prodromal signs in their children[169]. Current asthma management aims to devolve responsibility for starting or altering care on the patient and/or carer. The underlying philosophy is that the parent is best placed to recognise and alter treatment in response to deteriorating asthma recognised by observing an increase in symptoms. In young children, symptom recognition through observation is therefore a key carer skill.

Summary

In this chapter, the evidence from the interviews that the mothers were in a state of persistent alertness or watchfulness as their children experienced recurrent respiratory symptoms was discussed.

The next chapter moves on to describe mothers' experiences as they sought medical explanation for what they had observed. For many mothers a diagnosis of asthma was not forthcoming.

CHAPTER 5. SEEKING A DIAGNOSIS OF ASTHMA

Introduction

There are currently no objective diagnostic tests for asthma in young children. One reason for this is that young children (below 5 years) cannot, in the main, co-operate with tests of lung function that would provide evidence of variable airway obstruction that is such an important feature of asthma. This creates a real difficulty for doctors when confronted with a young child with new symptoms in keeping with asthma. In current practice, a diagnosis has to be made based on the presence of key clinical features, such as recurrent episodes of cough, wheeze, breathlessness and difficulty in breathing, response to asthma treatment and repeated reassessment of the child[21;180;181]. Other factors such as the presence of a family history of asthma or other atopic illness provide supporting evidence but are not in themselves diagnostic. The need for reassessment over time due to the episodic nature of asthma often leads to a delay in arriving at a clear diagnosis.

This chapter describes the mother's perceptions and action during the time from first symptom presentation to doctor diagnosis of asthma.

Emergence of the theme

In the first interview the mother participant S1 was asked "When did you first learn [child's name] had asthma?"

The mother's actual interview response was as follows:

> *S1: "He had RSV when he was 3 weeks old, and until he was 11 months he had problems with his chest and when he was 11 months old he came in here to have his blood tested to test his immune system. They discovered he had something in his blood that showed he had allergies and it was linked to asthma. They diagnosed him then and there and he was given inhalers… He was just 11 months and from 3 weeks till 11 months he had constant wheezing and coughing. They said it was quite unusual for an 11-month old baby to be diagnosed with asthma but he was so bad he needed his inhalers".*

In this response three potentially interesting points were noted:

1. The mother described experiencing a prolonged period of illness in her child, of around ten months in duration, eventually culminating in a diagnosis of asthma.
2. The mother described a blood test being performed. The result indicated the child was atopic, a condition commonly associated with asthma. Whether the presence of atopy would influence general practitioners and make them more likely to reach a diagnosis recurred as an issue in later interviews.
3. The child was diagnosed at eleven months of age at the local children's hospital. In the quote, the mother noted that the hospital implied this was an unusually young age for a diagnosis of asthma to be given.

As the interviews progressed it became clear there were clinical difficulties around reaching a diagnosis of asthma in a young child. That is the mothers repeatedly sought explanations for what was happening yet a delay in giving a diagnostic label was evident despite some of the children clearly presenting with signs typical of persistent asthma. There was often discordance between the mothers' view that their child had asthma and the view of the doctors. Two years old was emerging as the age at which a doctor would be prepared to give a diagnostic label of asthma.

As data collection and analysis continued the emergent factors were pursued. For coding and analysis, purposes they were identified as the following four categories:

1. Seeking answers
2. Delay in diagnostic, including the 'two years old' rule
3. Lay diagnosis of asthma, including the importance of risk factors
4. Doctor diagnosis of asthma

The chapter now focuses on an exploration of each of the four categories.

Seeking answers

The mothers sought a medical explanation for the signs and symptoms they had observed in their child. Most often they had approached their general practitioner,

often on a number of occasions. This was reflected in the transcripts through use of phrases such as "constantly taking her to the doctor", "always at the doctors", "I was never away", "when am I going to be back there again", "kept going back to the doctor". Some mothers gave actual numbers of visits. One mother (participant S15) told of going to the general practitioner and the out of hours at least four times each before a diagnosis of asthma was made.

During this period, the mothers' reported that visits to the general practitioner were frequently unhelpful. The mothers had a sense of being taken in and out quickly, and of being given different mixed up advice. The failure of the general practitioner to address the mothers concerns often led the mothers to feel they were not being taken seriously.

> *S11: "Aye I was up at them all the time. I was felt as if I was never away from the doctors and they give you a prescription and I felt I just want someone to take my wee boy and make him better, I wanted more, I wanted someone to sit down and talk to me explain to me".*

The fact that the mothers' did not get a label to explain their child's repeated illness adversely affected the mothers' perception of the relationship with the general practitioner. The mother's frequently commented that they developed a sense that they were being seen in a bad light, or labelled as problem patients or "neurotic" (first time) mothers.

In some, this created an aversion to returning to the general practitioner for further medical help. At their very height some mothers reported visits to the doctor occurred more frequently than weekly. The following mother described a 'bad time' when her son was particularly unwell and she had to make a number of visits within a short time frame.

> *S7: "I went to the doctor and I said I know I'm back again and he said this was his exact words he said you've been here 8 times in a fortnight and I said I'm not proud of it but there is something wrong with my child".*

Diagnostic delay

Many of the recurrent illness episodes described in the previous chapter were not severe enough to cause the mothers to seek urgent medical help. However, on occasion symptoms were sufficiently severe to lead them to toward medical services. Some families made frequent visits to the general practitioner, and/or the local Accident & Emergency department. During this early period, these visits often proved frustrating. Even though visits may have occurred repetitively over a relatively short time period, the illness episodes appeared to the mothers to be dealt with as single, one-off episodes rather than part of a larger problem. When seeking explanations about the underlying cause, the mothers often encountered barriers and as a consequence experienced increasing frustration and helplessness.

> *S9: "Terrified, really frightened, and helpless, cause I couldn't do anything about it, really helpless like I'm his mum and I can't do anything about it... You just feel really helpless and you want to do anything to help them. I wish they would call it something even if its not asthma, something".*

Frustration was expressed in the sense that the doctor was not acknowledging the bigger clinical picture and that the number of repeat episodes was not being recognised. Participant S20 recounted visiting the doctor on up to five occasions for the same complaint: "*Its over 4 or 5 different times that we go in for the same sort of thing*". Failure of a doctor to recognise a child attending for the same thing was not seen as positive.

> *S13: "I just feel there's a basic something missing with doctors if they don't recognise if I mean he was Dad's GP that guys been in practice for over thirty years you think he would be able to recognise if someone's constantly going back with the same coughing at night, that it could possibly be asthma".*

From the mothers descriptions a number of potential barriers to diagnosis could be tentatively identified.

The predominant barrier appeared to be the age of the child. In the first two interviews the mothers S1 and S2 had raised the issue of their children being under two years at the time and being too young to be diagnosed as having

asthma, although they had not specifically stated it as such. Six further mothers (S5, S7, S9, S12, S13, and S15) however made a direct statement supporting the understanding they had been given by their doctors that a diagnosis of asthma was not possible in a child under two years of age.

The idea that a diagnosis of asthma could not be made in the very young was supported in the interview with participant S17. Unlike the majority of mothers in the study her child first showed signs suggestive of asthma shortly before his second birthday. He became acutely unwell, with no prior suggestion of asthma and was taken to hospital. He received a diagnosis there and then.

> *S17: "He took unwell just before he was two and I had noticed his breathing his wee tummy was going up and down really fast and I was concerned that and that's when I had actually phoned [the hospital] and that's when they said bring him up, and that's when they discovered he had asthma they done all the checks and ended up on a nebuliser and they admitted him he stayed in for two days till they got him stable but we never had any indication before that he had asthma".*

This suggested that the closer the child was to two years of age the more likely a diagnosis of asthma might be. This idea that the age of two was a form of watershed age appeared as the mothers described their experiences. Everything seemed easier after the child had reached two.

The delay in receiving a diagnostic label was reported to occur even when a mother might specifically challenge the doctor and ask outright if it was asthma. Participant S18 described what had happened when she did so:

> *S18: "We did say "has she got asthma?" but they said they were reluctant to diagnose it when they're young ...they've got to give it time and see them repeatedly before they can say yes she has asthma".*

The second barrier to a diagnosis of asthma experienced by the mothers was that of being given an alternative explanation. Thus instead of committing to a diagnosis of asthma the general practitioner might play down the illness, or give an alternative label. Often an episode was described as an acute illness that

would be expected to be time limited, e.g. a cold, chest infection, tonsillitis, that could be easily treated by a course of antibiotic.

It seems quite likely that the doctors had either not appreciated or underestimated the detrimental effect that not providing a definite diagnosis would have on their working relationships with the mothers. Participant S18 described the situation as being "fobbed off".

> *S18: "Just that somebody was recognising and was able to say to us yes she's got asthma this is what we can do, this is what you can do and just making more information available to us rather than just being fobbed off by a GP all the time".*

Lay diagnosis

Undoubtedly, an important factor in the mother's feelings of frustration was the fact that the medical assessment of their child's symptoms was at variance with their own. The mother's reported a consistently high awareness of the diagnostic importance of the symptoms they were seeing. They themselves had often arrived at a diagnosis of asthma, based on their lay interpretation of the signs and symptoms. For example, participant S2 had specifically said early on that she "knew it was asthma" and it was simply going to be a matter of time before a doctor confirmed it. What the mothers had not expected was the length of time between their recognition that it was asthma and the doctor's confirmation of the diagnosis.

Ten mothers (48%) made explicit reference in their interview to knowing it was asthma. They had made a lay diagnosis in advance of the doctor. In the transcripts this was expressed in phrases such as "I recognised" "I knew" "I reckoned it was asthma" "I knew the signs".

The mothers could all describe a series of characteristic signs and symptoms: repeated illness episodes; often, in association with an upper respiratory tract infection; and signs of intermittent wheeze and breathlessness on exertion. This was so both in terms of signs observed in an acute and chronic situation.

Acute setting

The mothers commonly highlighted accurate signs of acute asthma, which they had identified during an acute illness episode in their child. The main symptom recognition was around wheezing and coughing. An example of how this was expressed follows. The mother described how she had taken the child to the general practitioner because she felt the constant coughing was something 'more' than a cold.

> *S5: "they're coughing and constant coughing your GP's said its okay he's fine he's only got a cold, yet you can see your child is very uncomfortable".*

Chronic setting

Some mothers spotted the significance of underlying signs such as shortness of breath and wheezing on exertion that would be typical of persistent asthma. These were reported to occur in two children despite their young age (the children of participant s S4 and S8)

> *S8: "I'd went to see if he had asthma when he was about 10 months I took him to our own doctor and I said I was worried because of his wheezing you know when he was crawling about he was getting out of breath and once he was walking it got worse he was wheezy after doing round the block once".*

Collectively, the mothers displayed a keen appreciation of the importance of what they saw.

Risk factors

The mothers had often taken account of the context within which the symptoms in their child were occurring. For example, they realised that a family history of asthma or other allergic illness was important and were aware of the strong association between atopy and asthma. This was not unsurprising in the mothers who had asthma themselves (who numbered 7/21). However it was not solely a feature found in these mothers. This well developed understanding may in part reflect a high degree of exposure to asthma and/or atopy within the sample [Table 2]. Only two of the eighteen mothers who experienced the time-lapse (participants S13 and S17) had no family history of asthma, hay fever, allergies or eczema, or of another child or family member with asthma.

Two examples of quotes relating to a family history of asthma and atopy are given. Neither of these two mothers had asthma themselves.

> *S2: "I think it's got a lot to do with both sides of our family having it, you know there's a very strong history so the first thing, when the wee one starts to cough that's the first thing you think of right asthma. Eczema runs in our family as well".*

And again:

> *S11: "I've eczema and my brother suffers from asthma… I thought afore then anyway cause they say asthma and eczema's linked".*

Doctor diagnosis

The period of delay finally ended when a doctor made a diagnosis of asthma. Based on the mothers' recollection of events, a doctor-diagnosis of asthma was received on average around the child's second birthday (Median age of doctor diagnosis 1.6 years, range 0.5 – 3.2 years) [Table 3].

The circumstances surrounding the diagnosis were fairly uniform. Whilst one mother was given a diagnosis by her general practitioner, (participant S21), the remaining seventeen received their child's diagnosis at the hospital either during another emergency presentation, or through a scheduled appointment at the specialist respiratory clinic.

An opportunistic diagnosis was received by some during an emergency visit to the local children's hospital for treatment of an acute episode.
The following are examples of how the diagnosis was received:

> *S1:" When he was 11 months old he came in here to have his blood tested to test his immune system. They discovered he had something in his blood that showed he had allergies and it was linked to asthma. They diagnosed him then and there and he was given inhalers."*

And again:

S13: "So they put her in a ward she was only in for an afternoon, but basically that was the point that they said they thought she was developing asthma so she was given the inhalers to take".

There was a sense in some that the general practitioner was reluctant to make a diagnosis and instead agreed to refer the children to the hospital. In some mothers it was seen as "lucky" to have been referred to the hospital:

S5: "Now I was very lucky as I had a GP who referred me and I was one of the lucky ones and I was seen by a very good consultant, who I could chat with".

One mother, participant S20, described how she pushed her general practitioner to send her to the hospital for another opinion:

S20: "No well really when I had says to the GP I'm kind of a fed up coming to the doctor you feel as if you were never out the doctors and there's oh he's saying she's just a paranoid mother that's like its your first child you're really paranoid he's only coughing but I'm saying something must be making him do this he's no coughing for nothing and then eventually I said to him what about seeing somebody about this and he said right fine I'm quite happy to refer you to the hospital to see somebody".

In practice asthma is often a diagnosis that is made after other serious respiratory illnesses have been excluded[21]. A mother very perceptively picked this up.

S13: "I don't know I think it probably is but sometimes I think maybe its something else, asthma's got such a wide spectrum... I think asthma's one of these things it's a case of ruling out other things rather than saying its not like you've got some other illness and they can give you a scan and look at it and say that's definitely what it is. With asthma it's a case of its not this it's not that probably its asthma".

Discussion - the Void

This chapter has described an identifiable period of time when the mothers felt they were working in a wilderness, without medical clarification or validation to help them make sense of their children's illness episodes. In this sense it might

be described as a 'Void'. Whilst the mothers did not specifically use the term Void it was retained as it was felt by the researcher to encapsulate the mothers' experience.

Uncertainty

The mothers' experience of a void is not unusual. Uncertainty in illness is common and is usually defined as an inability to attach meaning to illness related events[110;114;182;183]. Feelings of uncertainty and helplessness in the early stages of asthma have been reported before[110;111;113;114;183;184]. What may be unique to the mothers' situation here is that this uncertainty about the meaning of the respiratory symptoms in their children was then compounded by the reluctance of the health professionals to give meaning to the illness episodes they were describing. This may be particularly confusing and upsetting to lay people who expect professional confirmation in the form of a diagnostic label for those symptoms they take to medical staff.

Diagnostic delay

Diagnostic difficulties were commonly reported in the interviews. The mothers described the difficulties in terms of a delay between the time they first saw the doctor and the eventual recognition of asthma by a doctor. When wheezy illness first presents it is not clear whether a specific child will go onto develop recurrent episodes consistent with a diagnosis of asthma. However, diagnostic delay as defined as 'the interval between the first visit to the doctor with respiratory symptoms and the established asthma diagnosis' is not uncommon in childhood asthma and can last as long as three years[53;54]. In general, such studies have shown that general practitioners over emphasise infectious causes and over-rely on antibiotic therapy[53;54].

In this study, the mothers reported numerous illness episodes and inconclusive visits to the doctor. Similar experiences have been reported[109;110;185]. Presenting repeatedly for emergency care is associated with increased parental anxiety, as whilst the immediate problem is often fixed the longer term clinical picture remains unresolved[109].

In a recent study of thirty Danish children a similar pattern was reported[185]. Ostergaard interviewed parents of thirty children with asthma, and fifteen GP's in Copenhagen. Substantial diagnostic delays occurred despite eleven children having been hospitalised on more than four occasions. Failure was attributed to the general practitioner, and not the parents, for failing to take appropriate action when their children became unwell. The doctors were found to be reluctant to give a diagnosis of asthma partly because they did not expect asthma in toddlers and they felt uncertain about making a diagnosis and did not want to stigmatise the child. This was also true in the current Glasgow study where the mothers reported the general practitioners' emphasis being on the current presenting state, not on the long associated history. Ostergaard found that the absence of specific asthma signs (rhonchi/wheeze) in the consulting room correlated (in a qualitative sense) with absence of asthma as a diagnosis.

Such medical reluctance to diagnose in young children is compounded by the lack of objective tests. This leads to an emphasis on the need to see a recurrent pattern of symptoms. However, in this study the mothers did not appreciate the reasons for such clinical difficulties, or their relevance in delaying a diagnosis of asthma, nor was the situation explained to them in a way that might have facilitated discussion around the subject.

Lay diagnosis

In this study ten mothers reported that they had accurately labelled their child's illness as asthma in advance of receiving a doctor diagnosis. Of the ten, three had asthma themselves. This number of mothers making a diagnosis themselves seems to be an unusually high proportion compared to other literature reports. For example in a recent American study of eleven mothers, all of whom either had asthma or had been exposed to it through another family member, only one had made a lay diagnosis in advance of medical confirmation[186]. The Glasgow mothers therefore seemed particularly knowledgeable in this area.

In the period before seeking medical help, the mothers in the present study had first to recognise the presence of patterns of illness, and evaluate their significance. Three features of symptoms are known to be important in a lay persons illness recognition process: these are severity of the symptom, the

familiarity of the symptom and how long it lasts[187]. In this study the mothers showed a clear understanding of the importance of the type and frequency of the diagnostic clues they were observing. The diagnostic clues were very similar to those identified in the medical literature as being indicative of asthma[19;20]. Additionally, the mothers expressed what they were seeing in words such as "wheeze" and "cough". In Ostergaard's study some diagnostic discrepancies were attributed to parents using lay expressions and metaphors when describing illness in their children[185]. This could not be said for the Glasgow mothers.

Doctor diagnosis effect

Feelings of helplessness, fear and vulnerability in parents of young children presenting with asthma in early childhood have also been reported[109;110;113;186]. Such feelings are made worse when the assessment of the child's health is trivialised or ignored whilst looking for help and support[96;186]. Conditions are thought to improve rapidly once a doctor diagnosis of asthma is made and more effective management plans are initiated[109]. It is suggested the diagnosis provides a degree of legitimacy to the families and ends the period of uncertainty[111;182].

Non-void participants

Not all participants in this study described a void. Three participants, S3, S4, and S17 received a diagnosis of asthma soon after the onset of their child's symptoms. The three who did not experience a void were similar to the main group in terms of their child's age and overall severity. In each case, doctors at the local children's hospital had made a diagnosis of asthma.

The circumstances surrounding the three mothers were not all the same. In two of the families the children developed a rapid onset of symptoms, with no prior episodes recorded. One was seen at the out of hours emergency medical service and the other at the local children's hospital Accident & Emergency department. Both received a diagnosis of asthma there and then. Both children were under two years of age; S3's child was around one year old and S17's was nearly two. The remaining mother, participant S4, presented her child, at about six months of age, to her local GP with signs of persistent asthma, shortness of breath on

exercise, and chronic cough in the absence of upper respiratory tract illness. She herself had asthma, the child's father was atopic and both parents worked at the local Children's hospital.

In two children there was associated history of atopy either in the child or the parents. However, this alone was unlikely to explain the rapid diagnosis, as similar patterns of family illness were present in others. In Koenig's study, one mother who received the asthma diagnosis early did not necessarily do better[186]. Whereas in the literature a doctor diagnosis of asthma is linked to developing normality and function in the family in Koenig's study the mother struggled to come to terms with the diagnosis and expressed high levels of anxiety. There was no evidence of such a struggle in the three non-void mothers in this study. However, there was nothing at this stage to suggest that they experienced asthma more easily as a consequence of receiving the prompt diagnosis. In the absence of positive advantage from prompt diagnosis it remains unclear what gains could be achieved from a rapid diagnosis process.

What the data seem to suggest is that it might be helpful for doctors to at least acknowledge the possibility that something is medically wrong and offer a working label. The mothers in this study seemed able to comprehend that a diagnosis might be difficult, but struggled with the absence of anything in its place. Indeed participant S5 perceptively highlighted this and suggested that there may be a place for an individual other than a doctor whom could support parents around this difficult time. Acknowledging the situation may be the most crucial thing for mothers at this time.

> *S5: "I just wish that when babies are looked at very young and there's a suspicion there, and I use the word suspicion because nobody's ever willing to say whether its asthma until they are about two I wish, not saying it had to be your GP but there should be someone that you can go to in the interim, of say a 6 month baby-to two year old child and say this is happening it could be asthma so help us in between until we actually know and if you got that help or it can be explained at the early stages what it could be you may know how to cope with it. It may have given me an insight into what's happening with him rather than going on and these colds and sickness like the drop of a hat".*

Summary

In conclusion the experience of the majority of mothers in this study confirmed difficulties around arriving at definitive doctor diagnosis of asthma in a young child. Collectively the experiences in 'the Void' represent the start of many challenges that a family has to face and overcome when trying to integrate asthma into family life and regain a sense of normality[106].

The next chapter describes the development of self-regulatory skills in the mothers.

CHAPTER 6. GETTING TO GRIPS

Introduction

This chapter describes a qualitative exploration of how self-regulatory skills develop in parents of young children. It describes how mothers attain a state that in this thesis has been termed "*mindful self-regulation*". It describes both the route by which mother's arrived at this state and what mindful self-regulation represents.

Emergence of the theme

As noted in the Methodology chapter it was decided to be very clear about how the extracted themes linked back to the original transcripts. In this particular chapter, care has been taken to set out in detail a description of how the researcher came to recognise the early signs of data that were to become of significant theoretical importance.

Before conducting the first interview it was not known to what extent the mothers might use self-regulatory behaviours to manage their child's asthma or how such behaviours might have developed.

In the first interview, the mother (participant S1) was asked what problems she had encountered as a result of her child having asthma. In her response, she talked about the practical problem of getting help with care for the child from within the family. In general, she was reluctant to leave the child with other family members, fearing they would not respond appropriately if the child became unwell with asthma. However, she described one incident when her mother-in-law had come to the house to help, and spotted the child was unwell. Because her mother-in-law had been a children's nurse, the mother seemed to respect her ability and knowledge.

> *S1: "My mother-in-law she's fantastic… she was a sick kids nurse so I've learnt a lot from her as well about his colour and things like that. Because there's times when I didn't realise his colour and she came in one day and*

said his colours not good and she said I think you should take him into hospital now, so I brought him in and his sats were sitting at about 90/91".

At this point, the interviewer had asked this mother if the episode with her mother-in-law had been important in her future management of the child's asthma. The mother did not directly answer but instead went on to describe a later incident, which she considered an important turning point in her thinking. She described this as "*the time I really turned*".

[Interviewer] Was that a fairly important moment in terms of how you managed his asthma from that time on?

S1:"I think the time that I really turned was when I put him down to bed one night and he was fine, woke up at 6 in the morning went through to check him and he was grey, the doctor came out and dialled 999, that floored me".

[Interviewer] And you had to pick yourself up from that and learn how to deal with that once it was over?

S1: "I had to start thinking I have to prevent this rather than dealing with it when it happened".

This first interview brought to mind two preliminary thoughts. Firstly, the mother's description raised the idea that there might be an important moment (a 'turning point'), in which a mother's thinking or beliefs about asthma and its management might be challenged and changed radically. Secondly, it brought up the idea of 'preventing' as opposed to 'dealing with'.

This change from a reactive towards a more proactive strategy fits well with the underlying philosophy of self-regulation in which a parent might learn strategies to manage and prevent the child's asthma from deteriorating. It is also in keeping with the current treatment paradigm for asthma, which stresses the importance of prevention[15;21;24;180;181]. Both points were identified as being of interest and importance in thinking about how self-regulation developed.

Routes to regulation

Participant S1 had unexpectedly described a moment of immediate change in her approach to her child's asthma management. At this stage, it was not known whether other examples of sudden changes in thinking would emerge in subsequent interviews.

The next two interviews (S2 & S3) revealed a different progression in the development of the mother's asthma management skills. In the second interview, there was no evidence of a sudden turning point. This mother had an older daughter who had asthma and eczema in early childhood. She seemed to have grasped the concept of prevention from her previous experience.

> *S2: "My older daughter... she had both she's really doing well now compared to when she was her age it had never been as bad as hers (the child in the present study) but it was when she first started coughing at 2 and a half years and I just didn't know what to do and you know I'd bring her up and my doctor gave her the blue inhalers and that weren't helping her much and then she had the steroids tablets but once he gave her the brown inhaler originally it was the 50 micrograms that was one puff in the morning and one at night and that was okay for her and she's been fine since, hardly using the blue inhaler so all she needs is one puff before she goes to bed, the brown inhaler and she's fine".*

The third participant also made no reference to an immediate turning point. Instead she used words like "I've started to see patterns", implying a gradual accumulation of experience with time. She described changes in relation to the use of medication and to her sense of control. In her description, effective medication for asthma seemed important. For this mother, her change in behaviour resulted in feelings of lack of control being replaced by those of empowerment due to her ability to predict the short-term course of her child's asthma.

> *S3: "As soon as we got medication to control it I felt okay we just, although I am concerned about using medication and side effects of them short term and long term, but I just felt I had to do that she needed the medication so I suppose I felt it was more under control and now that she can tell me when*

she's getting wheezy it's in some ways easier to deal with because you can catch it earlier and its not as out of the blue plus I've started to see patterns she's more likely to get it in the winter, so I think it's very much about feeling in control".

The first three interviews were reassuring because they confirmed that evidence about the development of self-regulation was present within the interview transcripts.

Development of Self-regulation: Incremental or Instant

This preliminary evidence suggested that there might be more than one route to developing self-regulation skills. The second and third interviews performed described a stepwise progression to change, involving a slower and more incremental process. However, the first mother's description of a sudden change was quite different. This evidence from the first interviews that there might be more than one path to self-regulation was clearly of considerable theoretical interest.

To pursue the idea of different paths in the development of self-regulation in more detail in later interviews, all subsequent participants were probed on how they learnt to manage their child's asthma. The following are examples of the questions used to explore this theme in future interviews.

How have you learnt to do this?
Are you doing things differently?
How did you learn to do that?
Do you have a plan of action?
How did you get to be like that?
Have your actions changed over time?

However, often issues arose unprompted. To explore this line of inquiry in the data any description in the transcripts that seemed to be related to the development of self-regulation was first coded as 'developing self-regulatory practices'. A sub-level of coding within this was developed regarding references to the types and dynamics of change or turning point moments. A response was labelled as incremental if it contained descriptions or words such as "I've started

to see patterns", "over time", "in stages", "add it on", "build it up". Conversely, a response was labelled 'instant' if it used imagery that denoted a revelation, or sudden change in position, and the language signalled a strong emphasis for example "the time I really turned", "it just clicked", "a wake-up call". As the interviews and analysis progressed, examples of both types of routes to regulation, "incremental" and "instant", were noted. Without excluding other options it was possible to classify all mothers into one category or other.

Incremental group

By the end of the study, a group classified as 'Incremental' numbered 16/21 of the set studied. The following is an example of incremental change, and factors affecting it.

Participant S5 was classified as incremental because she used terms like "by addressing it in stages" in her narrative.

> *S5:"And by addressing it in stages I'm at the level I'm at now. It was addressed in stages I was lucky...During the period of hospitalisation and going to the clinics I was beginning to understand a bit more, I had lived with it for a bit longer I had seen what happened when he was admitted to hospital on a few occasions I was seeing the treatment, start and finish and him getting better".*

Further on in the interview she was asked: "How have you learnt to do this?" She gave a detailed and comprehensive response (which follows below). This can be analysed to identify specific activities/behaviours, which might be relevant to the development of self-regulation. These steps were then explored further in later interviews.

> *[Interviewer] How have you learnt to do this?*
>
> *S5: "I take it very seriously, because I'm the only one, me and my husband, I'm the only one who can make a huge difference with his asthma. Because if I was slack or wasn't picking up as I do he could become into a scenario of having more attacks if I wasn't as strict with his medication, no pets he could be coming into contact with things he shouldn't be I feel with having a lot of control over his lifestyle just now that I can control his asthma to the*

best of my ability I feel it's a huge part of being a mother that I have to take control of this, who else is going to. You cannot go to the hospital all the time and expect these people to do it they're not with you 365 days but once you are discharged from hospital you have to take control, it has to be in your best interests to try and learn about it and I want to learn more and more so that I can help even more".

In this "incremental" change group, the data suggested that a model featuring a steady progression provided a good fit for the process described by the majority of mothers. The data also provided key actions and behaviours (factors) that might influence movement through the experience.

Factors which may affect progression

From the full incremental group data set, a list of common factors influencing progress to becoming self-regulatory key actions/behaviours that the mothers highlighted as important was compiled.

1. Taking it seriously
2. Being strict with the medication
3. Taking responsibility "You cannot go to the hospital all the time"
4. Being conscientious, picking up on things
5. Avoiding known triggers
6. Learning as you go along

These were later contrasted to factors described in the "instant" group and following completion of the analysis with the Zimmerman model.

Instant group

By the end of the study five out of 21 participants had been classified as 'Instant' (participants: S1, S10, S13, S15, S21).

Because the change process in the five mothers differed from the other participants, the 'instant episode' was examined for unique peculiarities and similarities within the five participants. Participants S1 and S13 linked it to a serious sudden episode of asthma in their child for which they had to call 999. Participant S15 described it as happening after the child had had a hospital admission, and participant S21 after an urgent out of hours visit to the local Accident & Emergency department. For participant S10, it was associated with a visit to the Consultant clinic at the local hospital.

With the exception of one participant, S10, the excerpts had two similar features. Firstly, each described a sudden change in thinking related to the concept of regular asthma treatment. Secondly, for each there was an acute event, which was associated with triggering it.

Participant S10 was also of interest because although her change was classified as instant she showed a key characteristic of progression that Zimmerman mentioned in his model – namely, a change in her perception of self[85]. In her transcript this was expressed as changing into a person who is more equivalent to a nurse than a mother.

> *S10: "Maybe there's a lot of people like me and it just hasn't clicked, it just hasn't clicked that this is a condition that you find in your house that your child is going to have forever and you're gonnie have to deal with it, and that turns you into a person that's gonnie really know about that subject like the nurse does because I always see myself as you go along to the doctors for help and they help you and that's fine you don't need to know what they know you only need to go and get the medicine and come back and your better but asthma's not like that and that's something that I've realised that okay I need to know about that I need to know what he can have what he can't have and where the boundaries are, what I can deal with and not finding out over a period of 6 months what that is but just somebody taking you aside and saying right this is what it is this is what you can do and giving you a bit of confidence yourself because it would like if I for instance became a diabetic and I had to give myself injections I would suddenly become I mean I would feel as if I was a nurse if I had to do that because so I think it's a bit like that with asthma really.*

Additionally because participant S10's instant change process had occurred out-with an acute asthma situation, the transcript of her interview was examined in further detail. This mother had an older child with asthma thus one might have assumed that she would have already 'changed' during the process of learning to manage her older daughter's asthma. However, in the transcripts she talked as if she was encountering asthma for the first time, a point noteworthy because it suggested that the mother had not been able to transfer her asthma skills from

one child to another. This was of interest as self efficacy is also known not to be transferable from one situation to another, rather it has to be built individually[121].

Factors which may affect progression

As in the incremental group, a list of common factors in the instant group influencing progress to becoming self-regulatory was compiled. The following points that seemed to be important in this group were distilled:

1. Taking it seriously
2. Giving the preventive medication
3. Taking responsibility from the health professionals
4. Increased confidence in own ability to influence disease course - avoiding triggers and acting appropriately
5. Change in perception of personal identity from 'mum' to 'expert mum'

With a mother in the instant group showing a characteristic linked with the incremental progression it suggested that factors of influence on becoming self-regulatory might not be directly related to the route to regulation the mothers took. That is the route may vary but underlying factors of influence on progression may be common across the group. Indeed, across both groups there was some qualitative evidence of common factors of progression. This prompted a further examination of factors influencing progression in both groups and is addressed in the following section.

Factors of influence on progression toward self-regulation

This section compares factors thought to be important in self-regulatory progression in the incremental and instant groups in relation to those described in the literature by Zimmerman. The comparison was undertaken following completion of data analysis, in order to review the findings in the context of current understanding of parental self-regulatory development.

To recap the Zimmerman model of parental self-regulation development describes a sequential process with four unique phases. The model states that key to progression through the phases is a parents' ability to[85]:

1. Change fundamental beliefs about asthma
2. Change self-perceptions of vulnerability

3. Enhance perceived self-efficacy for coping with symptoms
4. Change daily routines, the home environment and interactions with others (namely the clinician in charge of the child or the asthma consultant)

In this study, the common factors linked to progression in both incremental and instant groups were:

1. Taking the asthma seriously
2. Recognising the importance of giving the preventive medication
3. Actively taking responsibility or control from the health professionals
4. Increased confidence in altering the course of the disease (in relation to keeping the child well month to month rather than life-long)

In the next section, each factor of progression identified from the current study is discussed with supporting evidence of its presence and degree of incidence, and where appropriate contrasted to the Zimmerman model.

Factor 1 - Taking the asthma seriously

In the current study, there was evidence that an awareness of 'seriousness' was an important factor in the change and further development. Seriousness in the context of asthma meant recognition by the mothers that asthma was a potential life threatening disease. Fifteen mothers made specific reference to realising asthma as a serious condition as an important factor linked to their personal development. This was seen across both groups as evidenced by the transcript quotes below. The remaining six mothers did not use the word 'serious' outright but there was instead an implied understanding of seriousness conveyed in phrases such as "*I never get complacent about it*" S18.

The following two extracts provide examples of how beliefs about seriousness were expressed in the transcripts.

> *S1: "I didn't quite understand I'd never known anyone with asthma, it's never been in the family. I probably didn't take it very seriously at the start because you hear people say all the time I've got asthma and I didn't realise what I was in for to be honest".* (Instant change group)

S8: "I think everybody just thinks it's really common now it's not like if you say you've got cancer, if you say asthma its like everybody in the worlds' got asthma now so I think everybody in the streets got it, all the kids have got it. I think a lot of people don't realise it can be so serious at times". (incremental change group)

Hence, the mothers had a clear awareness of the risks of asthma. Sometimes, they recognised that these included features of a serious, life threatening illness such as a serious intensive care admission or death. Again, two examples illustrate the point:

S9: "Well now it would be that he went to ICU. I didn't know asthma was that serious, like people say to you oh its just asthma, people don't know. Asthma doesn't get seen like a serious illness, but I know this affects us really bad".

S6: "What I really worry about if he does take it he gets really severe or they can't do anything to control it and help him. You know that he gets really, really bad, and maybe has to stay in hospital, that's my main one I always as soon as they mention the word asthma and that I say right lets hope we've caught it at its early stages and we can deal with it ourselves that way we know how. Because you do hear of people taking asthma really, really bad and I don't know I've heard people saying that they can die of asthma they take a severe, severe attack but I know he's not any where near that and I hope he never gets to that stage".

It would be important to stress that all mothers in this group had children who had experienced a hospital emergency room attendance or at least one admission. Some of the children had multiple admissions, as is so often the case in young children at this age.

In Zimmerman's model, a key factor in progression through the stages was suggested to be a change in fundamental beliefs about asthma, namely moving from seeing asthma as a temporary intermittent disease to accepting it as a serious chronic condition[85]. There was little support in the current study for a belief that asthma was permanent in the sense of life-long as used by

Zimmerman. The interviewer asked all mothers whether they thought the asthma would have a short or long-term. Whilst some thought it may be around for the long-term "*S1: I think it's a long-term thing*", there was equal support for the idea that it would at least improve with time "*S9: I hope it goes away but I don't know, I hope so. I still have mine. I think when he's five it might change, because your body changes*" / "*S11: I think it'll always be there but it might not always be as bad as what it was*".

Factor 2 - Recognising the importance of giving the preventive medication

In general, asthma can be controlled through the use of daily, inhaled steroids, commonly known as preventive medication[15;21;24;181]. In all 21 interviews there was an acknowledgment of the importance of the role inhaled steroids play in controlling the asthma on a daily basis. Giving daily treatment did not always sit easily with the mothers, with frequent references made to concerns about side effects.

> *S3: "I know a couple of times I have questioned the side effects, and it's very much she needs this, it's much better that she has a low dosage of preventative Becotide than a flare-ups allowed to happen because we just don't know".*

To be effective inhaled steroids have to be taken on a daily basis[188;189]. The mothers appeared to have grasped this concept.

> *S14: "Yeah, it has because I mean it was a very deliberate decision to give her Becotide regularly rather than having this high dose of steroids every now and then".*

There was acknowledgement that taking a steroid inhaler helped to prevent attacks.

> *S18: "It's a necessity I don't want her to take attacks all the time she's got to have that".*

This participant was asked if she'd ever thought about stopping the steroid inhaler. She admitted she had, as the child had been well for a while. She described how the child had gone downhill.

S18: "Quite quickly, over about a month I'd say she was quite bad because we thought and then we realised that when you're okay you don't stop giving them it you keep giving them the preventer".

Factor 3 – Actively taking responsibility or control from the health professionals

In Zimmerman's model, this factor would relate to his 'changed self-perceptions of vulnerability'. In the present study, there was similarly a sense of a shift in responsibility of care, tied up with the mothers' growing sense of control, which in turn acted to reduce feelings of anxiety or vulnerability.

In general, this was described explicitly, as a change in personal identity by developing skills similar to that of a health professional, perhaps a move from 'mum' to 'expert mum', or more subtly through the descriptions of care that the mothers described in their transcripts. In at least one case, the mother (S10) actually likened herself to developing skills similar to that of a nurse. In both examples, there seemed strong support for taking on added responsibility for the child's asthma care rather than relying on emergency care, as the mothers might have done at the start of the child's asthma experience. Fourteen mothers provided at least one clear example of how this had occurred for them. All the mothers also provided examples of how they had taken on board the main responsibility for their child's care by learning what to do with the asthma medication regimen.

The following extract is an example of a mother describing how she had developed skills around the effectiveness of acute treatment:

S17: "Well I normally give him 2 puffs is normal but if he's really bad I'll give him 4 possibly 6 now I've not had that for a long time because over the year he's been getting maybe 2, but if I thought no he cough, cough, coughing, because sometimes when he's coughing he's sort of like gagging and he's making himself sick and but if he got and he wasn't you know he was really unhappy like that again I would check his breathing. Dr told me that if I check 40, [breaths per minute], over 40 that's definitely asthma because sometimes I was checking him and he was maybe 25 but I thought is that asthma but now I know its not its but if he was breathing over 40 I would and it wasn't getting any better I would definitely take him to the hospital".

She had accepted the responsibility of increasing his emergency treatment, and had even learnt how to count his respirations as a barometer of his response to treatment. This is an example of advanced home care. She also shows a clear idea of the limits that would lead her to hand over responsibility to the hospital.

For others, the original idea of control had come from a health professional but had been taken on board.

> *S4: "He wrote that into the plan and said this is just the start of the asthma your job is to go away look and observe see if this is right tweak it and modify it and phone me if it's not right and so the plan was slightly modified over time and that sort of thing but it was probably quite scary I have to say because he didn't just take control of the asthma he made it very clear it was our job to take control of the asthma on ****'s behalf he would give us some strategies and treatments that would work but we had to decide when it was appropriate to do it and it was quite scary as in some ways you hope you come up to the hospital the doctor would give you some treatment to take away and the doctor would manage the asthma whereas he made it very clear that we would have to manage the asthma that no one would be able to assess those symptoms in the way that we would".*

In summary, all the mothers described exhibited examples of how they had approached and accepted responsibility for the care of the child in the home. None showed any sign of over reliance on health professionals. Neither did the data suggest that they had taken on duties inappropriate to their skill level.

Factor 4 – Increased confidence in altering the course of the disease

Self-efficacy is the belief that one can carry out a certain behaviour or action. It is not a generalised response but rather is specific to a given behaviour[121]. It is known to be closely linked to self-regulation by providing confidence to the individual they can act to achieve a desired outcome or goal[81].

In this study, there was evidence to support the mothers' increased confidence in attending to elements of asthma management. This was largely in the use of medication in response to signs, treating episodes promptly and effectively, thus

averting an asthma crisis. In seven mothers (33%) the words "confidence"/"confident" were used during the interview.

The participant S1 talked about confidence in the sense of learning from a previous experience where she had not used the nebuliser promptly. She implied she now had confidence to intervene early and avert a worsening of the child's condition:

> *S1: "I think as well its trying to keep one step ahead, what's made it easier now for me is because its really just learning from mistakes. From leaving things too long maybe not nebulising him as quick as we should have done but it's a confidence thing".*

Participant S10 talked about confidence in her ability to give the child his daily dose of inhaled preventive medication:

> *S10: "Aha, being on the two (puffs of inhaler) night and morning I feel quite confident that I can do the two but I'm aware that its better if he only gets one from the point of view that he's not taking as much medication so if he can be healthy with one that's better its just a case of looking and seeing how he's coping with it all".*

Participant S4 talked about confidence in the positive action that the child's medication would have on his symptoms:

> *S4: "Maybe if I was less confident about what was going to happen when I gave him medication I might be much more anxious around it all I don't really know… I think now we probably have an idea of when his symptoms don't improve that he really does need extra help and we've learned with experience if we really do it quite quickly it reduces the whole course of the asthmatic event".*

Participant S17 provided a further example of a mother now having confidence in the effect of acute asthma medication:

> *S17: "I definitely feel a lot more confident with it now than what I did two years ago. Like two years ago if he started coughing or was sick I was really panicking but now I know giving him this (the blue inhaler) and it'll probably work and bring him okay".*

There was an expectation that over time confidence in the value of the medication, and when to give it, increased, irrespective of which group.

In summary, factors influencing the developmental progression in asthma self-regulation could be easily identified from the transcripts. There were some close similarities with those proposed by Zimmerman. The first three factors were evident in all transcripts irrespective of the suddenness of the change that the parents' described.

Mindful self-regulation

In addition to defining two routes to regulation, the transcripts also offered some insight into the mothers' thought processes associated with becoming self-regulatory and how they put self-regulation into action (e.g. in their expressions of sayings such as: "I had to start thinking about preventing this rather than reacting acutely").

In the self-regulation literature, Demetriou defines what he calls a state of "mindful self-regulation"[179] (Page 211): "Systems able to grasp and represent underlying relationships provide flexibility because they enable the individual to view a given pattern of stimuli from the perspective of other perceived or remembered patterns. Thus mindful self-regulation is necessary as a means to minimise the likelihood of error".

Such a definition offers a potential thought-model underpinning self-regulation activity. There was evidence in the analysis of the interviews, that all the mothers had reached a state of mindful self-regulation similar to that described by Demetriou.

Mindful self-regulation was seen in the data in two forms. Firstly, where the mothers openly described a thought sequence such as "I had to start thinking I have to prevent this". Such descriptions could be seen as a direct representation of a grasping of the underlying relationship between a sequence of events/action and associated outcomes and the purpose of regular preventive asthma medication. Secondly, and perhaps more subtly, there was evidence of mindful

self-regulation expressed within the examples of care and experiences that they described in the interviews. In a number of situations, they seemed to recount a sequence of events and outcomes that represented their understanding of the underlying relationship between engaging in certain asthma actions to achieve a particular good health outcome. Put simply, this might be regarded as representing a sequence similar to a mathematical formula which could be expressed as 'a + b ⇨ c.

Examples of how this was expressed in the transcripts follow.

> *S15: " Well I just had to think right okay take this very seriously and like using the brown inhalers … so I think that the one thing just getting into a daily routine making sure she has the brown inhaler which we've been quite particular about and using the blue inhaler if she's coughing and stuff using it at night time before she's going to bed because she's got a cough just now so probably just that type of thing".*

In the quote above the mother (participant S15) described a sequence, which she had realised was a way to achieve better asthma control in her child. Extracted from the quote the formula in this situation might be read as "Take the asthma seriously" + "get into a routine" + "give the right inhaler for right asthma sign" ⇨ "end up with better asthma control".

Demetriou talks about mindful self-regulation as a means to minimise the likelihood of error[179]. In the following example, participant S18 describes her application of exactly that, using mindful self-regulation as a means of reducing the likelihood of asthma error, error here is expressed as the occurrence of an asthma attack. The mother describes anticipating a problem (early signs of an asthma episode coming on) + her response (upping the dose of inhaled treatment) ⇨ and the expected outcome stopping the asthma from getting worse.

> *S18: "Just cause we know now right give her it at this stage up it straight away rather than waiting letting it get worse and worse before upping her dosage…Yes if we can anticipate it we can stop it".*

Once a state of mindful self-regulation was attained it provided opportunities to engage in predictive action through re-applying remembered patterns to developing new situations e.g.

> *S12: "You pick something up or if something happens you say well I'll*

remember that for the next time".

It was not always successful and refinement was learned. A mother described her expression of this:

S19: "We've done things badly, we've left it too late".

[Interviewer] But do you use that experience for another time?
S19: "You do, you're adding it on, you build it up, you make mistakes and sometimes you're not sure".

This concept links closely with the anticipatory nature of self-regulation where forethought is used to pre-empt problems and alter or affect outcomes. The theoretical implication is that mothers have developed an internalised formula or model for asthma management.

In some participants, the formula approach was well developed. S4: spot early signs + intervene early ⇨ try to stop an asthma attack. In this following quote the mother describes being on the look out for signs of trouble. Spotting a runny nose, which she suspects indicates a virus driven respiratory tract infection, and intervening with anti asthma treatment.

S4: "We have to be on our toes looking out for symptoms developing and I suppose when he starts to get a runny nose I'm already thinking there's a virus in his airway lining I wonder if this is the one that's going to start to trigger and irritate his airway… but the minute he starts to get a snuffly nose we start to become alert about other symptoms if he starts to get a bit of a cough and puffed we start to increase his Salbutamol and prophylaxis and now we're quite aggressive as soon as anything starts to develop".

Connection

In this chapter two key findings were described. The first related to the route to self-regulatory development and factors that influence progress. The second presented the reaching of a state of thinking, called mindful self-regulation, which included the mothers' development of an awareness of a sequence of events, and associated outcomes. Together they have been given the title "Connection".

The term 'Connection' was used by the researcher, because, it denotes a linking of the two findings in order to progress to a higher level of asthma management.

In the literature on self-regulation making the link between strategy and outcome is a key component underpinning self-regulation[79;84]. Thus Connection has an important role in the development of self-regulation by proxy in mothers of children with asthma. It describes an important gateway between an individual who 'does' versus an individual who 'comprehends' and derives strategies to manage the child's asthma'. In this sense it may represent an important point of distinction between self-management and self-regulation. A distinction not always made clear in the literature or in clinical practice guidelines.

Discussion

As discussed at the start of the chapter the only theory about the development of self-regulation in parents of children with asthma comes from Zimmerman's work. The findings described here support many of his conclusions and descriptions. For example, many of the influencing factors that Zimmerman suggests were evident in the interview transcripts.

What the present study also provides, however, is a number of challenges to Zimmerman's model. The challenges are made in respect of (1) the dynamics of change in behaviour, (2) the order of criteria used to identify the respective four phases to competence, and (3) to the factors that affect progression through the four phases; in particular beliefs about disease seriousness rather than chronicity.

(1) The dynamics of change in the path to self regulation

A key underpinning assumption of the Zimmerman model is that there is an incremental progression to competence. Progress is also ordered and follows a particular sequence. In the present study, two routes to regulation emerged. There was evidence that in the main many parents developed self-regulation incrementally. However, there was also evidence of a sudden change in behaviours, which five mothers experienced.

Whilst not common, there are a number of other descriptions of sudden change in the behavioural literature. In psychotherapy, Miller has described the phenomenon of quantum change[190]. From studies of alcoholics in the USA, Miller describes sudden and enduring change that affects a broad range of personal emotion, cognition, and behaviour. He calls it 'quantum leap change', and describes two types; sudden insights and mystical epiphanies, both of which could leave an indelible imprint and often lead to lasting and pervasive change. Whilst the underlying processes are complex, Miller suggests that quantum leaps are recognisable in the qualitative terminology of statements like "it just happened", "I just decided". This matches very closely with some of the terminology the mothers in the instant change group used in their interviews. For example "it just clicked" (participant S10) and "a wake-up call" (participantS13) suggesting a sudden insight.

Given the limited knowledge in the particular area of parental self-regulation it is highly likely that there may be more than one route to the development of self-regulation by proxy, and more variance in parental behaviour than initially expected. It is not known if a larger population was studied whether this might reveal evidence of even more routes.

(2) The order of the criteria used to identify parental phase position.

Zimmerman provides distinguishing criteria that are used to classify which phase in the self-regulation journey the parent has reached. For example, at Phase 2 one of his criteria states that the parent accepts asthma symptoms as a manifestation of an inherent physiological vulnerability and at Phase 4 they can identify early warning signs of inflammation (i.e. an exacerbation coming on). In this study it seems that both the acceptance of asthma as a diagnosis and the development of vigilance came much earlier in the mothers' mental journeys.

(2.1) Place of diagnosis

Although not directly stated, Zimmerman's model of the development of self-regulation seems to assume that a person starts on the path to self-regulation with a diagnosis of asthma already established and asthma treatment in place. By placing acceptance of a diagnosis of asthma so early in the development of parental self-regulation (at Phase 2) Zimmerman's model may have unwittingly

restricted its capacity to explain what happens in the time immediately before a diagnosis is given.

As seen in the previous chapter for the majority of mothers in this study, a medical diagnosis of asthma for their young child was not forthcoming early in their experience of asthma in their child. In practice, a definite diagnosis and appropriate treatment often did not follow a linear pattern with the introduction of treatment sometimes preceding the diagnosis. Here a model such as Zimmerman's, which is predicated on a linear progression, is at disadvantage.

(2.2) The second challenge to the order of stages relates to the development of key skills of observation, in particular monitoring of symptoms.

Zimmerman's model places 'identifying early warning signs of attacks at final fully self-regulatory competence level'[85]. In this study, as seen in the first results chapter, the skill of vigilance came early, and appeared to predate a doctor diagnosis or even the first signs of illness. Indeed, the evidence in this study suggests that mothers are already natural observers, and thus their vigilance and observation would be at the start of any process.

(3) The factors of influence on progression may be incorrect

Zimmerman's model works on the premise that to progress to a fully self-regulatory state a parent has to change in part underlying health beliefs. While recognising the importance of giving preventive medication, actively taking responsibility and increasing confidence in altering the course of the disease were all seen as factors of importance in the process change. However, the idea the parents had to adopt a belief that the asthma was permanent and treat is as a life-long condition was not evident. In this study believing asthma to be serious, rather than permanent, seemed to be more of a stimulus in the mothers' development.

Beliefs about medication are thought to affect adherence to treatment[92;191;192]. It is of interest that the mothers in this study all declared a sense of the importance of the role and purpose of the inhaled preventer treatments. In studies of adults,

non-adherence to treatment has been linked to doubts about the necessity and side effects of the medication[191;192].

Differences between study populations

Some differences in findings may be due to differences in the two populations studied, not necessarily deficiencies in the theoretical model. Firstly, Zimmerman's subjects were a predominantly Latino, deprived inner-city American population, and older (N=102, Median age 7 years, range 2-19 years). In the current Glasgow study the children were younger (N=21, Median age 3.9 years, range 1.13-4.9 years) [Table 3]. Whilst the mothers studied included some from areas of high deprivation, the group may have represented a wider spectrum of socio-economic groupings including those that were materially well off.

Zimmerman's subjects were classified as "having persistent asthma". However at recruitment his investigators had no access to information from lung function results or the prescribed pharmacotherapy for the children so it is not known how they knew the children had a 'persistent asthma' phenotype. Knowing this would be important because if the Zimmerman group of children included some children with transient asthma symptoms associated with recurrent viral infections it is feasible that parents of such children might not have seen asthma as a long-term disease. They would have been disadvantaged by the criteria used to assess their progress through the phases by being compared to parents of children suffering from persistent asthma symptoms. This may in part explain why so few parents in his study were classified as being self-regulatory. In a sense his model may have been overtaken by the growing scientific realisation that asthma is a heterogeneous condition with a number of different patterns or phenotypes of disease, all currently subsumed under the one asthma label[19;20].

In the Glasgow group of mothers, there was a particularly high degree of inherited link to asthma with seven mothers having it themselves, and only four mothers who had no history of asthma or atopy themselves or in their husband/partner or another child [Table 2]. There may have been some advantage gained by this high level of previous exposure.

Summary

In summary within this chapter evidence has been presented to show that two types of change along the path to regulation co-exist. There was also strong supportive data for the mothers having reached a state of mindful self-regulation. By accepting the seriousness of asthma in their children and high awareness of the role and need for preventive therapy one might suppose that this would at the very least provide a positive environment within which to support adherence to treatment regimes. Additionally accepting seriousness of illness may be important in the wider context of disease prevention behaviour. The mothers in this study described a wide range of things that needed to be developed or adopted in order to develop mindful self-regulation. In contrast to Zimmerman's focus on changing health beliefs, these were often practical: for example getting into a routine with the medication, fine tuning strategies as you go along, and developing a range of things to do.

However, there are a number of problems with trying to develop theoretical models for parents of children with asthma who are developing disease management skills. Firstly, the parents are acting by proxy, and in general are expected to develop new disease prevention behaviours, and practical skills, rather than changing existing personal behaviours. At present Zimmerman provides the only model to explain how the process of self-regulation by proxy might develop. His model has similarities to known models of incremental change[193]. Developing such a model for asthma may be appropriate; however given the lack of wider knowledge on how parents develop in this area basing a stage of asthma change model on an adult model of self-change may have restricted the theoretical fit of the resultant model.

In this chapter evidence of two routes to self-regulation was presented. There was evidence that whilst most mothers developed self-regulation incrementally, five mothers experienced a sudden change in behaviours.

The next chapter moves on to describe the mothers lay models of asthma.

CHAPTER 7. LAY MODELS OF ASTHMA

Introduction

As was seen in the Introduction how an individual experiences and explains illness affects their disease management behaviour. In particular adherence to preventive asthma treatment has been highlighted as an area highly influenced by personal views held[94]. In the current study it was seen as important to assess how mothers' beliefs about their child's asthma might affect the development of self-regulation.

Thematically the current study was interested in any interplay between development of self-regulation and lay beliefs, and how mothers' models of asthma contrast with the known biomedical model. Prior to the current study little was known about the beliefs of parents of young children with asthma living in Glasgow, nor whether their beliefs influenced (positively or negatively) development of self-regulation. This final qualitative results chapter investigates the mothers' beliefs about asthma, their lay practices and their influence on developing self-management skills.

Additionally, because some of the mothers had asthma themselves, information was available about a possible 'by proxy in a mother with asthma' effect. The self-regulation literature lacks information about the 'by proxy' effect and assumes that an adult acting on behalf of his/her child will behave in the same way as for one's self, not allowing for a potential difference when adults act on behalf of their children.

Emergence of a model

As described in Methodology the interview guide included questions designed to elicit the mothers' views about their child's asthma. There was an expectation therefore that by using questions defined by Kleinman[103] information around beliefs and/or explanatory model's held would be forthcoming.

The Lay Asthma Model

As the interviews progressed, it became clear that the mothers were capable of describing their mental images of asthma and of demonstrating quite a sophisticated understanding of the underlying disease process, and medication action. These were assembled to produce a 'mothers model of asthma', which was contrasted with the biomedical model of asthma. The mothers' model included ideas about the underlying disease process, symptom production, and disease causality.

Firstly, the mothers demonstrated a basic understanding of the anatomical structure of the lungs.

> *S9: "Well this is how I see it right, it's like a tube going to two tubes which get all gunky, all gunked up when his asthma comes on all this gunk gets blocked up and he canny breathe properly".*

Asthma is known to be a disease affecting the small airways and associated with recurrent airway narrowing, underlying inflammation, and symptoms of cough, wheeze and breathlessness. The mothers' descriptions of asthma included all the traditional clinical features of the disease: episodes of cough, wheeze, and breathlessness. Their explanations captured the dynamic nature of the pathological process in asthma with variable airways obstruction, associated with inflammation and a build up and dispersal of secretions. The concept of airway narrowing was seen in the use of words such as "narrow, tight, constriction, and closed" which were present in all transcripts. An example follows.

> *S3: "I suppose I think of airways constricting and there's things like dust mites causing the constriction and when I see her asthma deteriorating getting worse I imagine that getting tighter and finding it more and more difficult to breathe".*

Intonations of colours represented underlying disease activity; e.g. redness equals inflammation.

> *S14: "The airway and then the bubble getting red or tight"*
>
> *S9: "It gets all red and firey"*

Symptoms arising

Whilst there were many references to wheezing, the dominant symptom reported by the mothers was cough. The cough could be dry, persistent, sometimes chesty, and typically worse at night. Additionally there was a sense of congestion (in ideas of productiveness, wetness and the build up of thick fluid) as well as tightness, in the chest. This was often described as "mucous", or in made-up lay terms such as "gobby" and "gluppy". Examples of the use of both follow.

> *S11:"See when he was a baby we used to say mucous so I just say mucous but see when he's really wheezy I think it's like a puddle type thing, all inflamed about his chest. Its making it hard for him to breathe, it's like there's chewing gum stuck to his chest all the time that's he's trying to breathe and therefore its making it dead difficult for him".*

Two examples showing the idea of mucous production alongside the airway narrowing and the lay terms given to the product:

> *S4: "Yes I certainly see the lining of his lungs becoming red and swollen when he has these I imagine him to I suppose because I have asthma myself I imagine him starting to feel a bit tight and gobby getting a bit kind of phlegmy but not the way you would with a cold and I imagine his airways looking red if I could look in his airway I imagine it looking red and swollen and his airways become constricted there's less air getting in for every breath so I do have a picture of a process which has made his lungs swollen and itchy inside".*

> *S5: "Then he will start coughing it will increase and then what I understand, a build up of mucous, inside their bronchial tubes and so forth I imagine would get so thick and globby and gluppy that it restricts his airways. Therefore his chest is so congested with this gunge".*

Causality

Underpinning the mothers disease model of asthma were ideas about causality. Again this was of interest in relation to any diverse health beliefs the mothers might hold which might have affected their progression to self-regulation.

All of the mothers held views about cause. It seemed important to them to attribute a cause, and something that they had considered. For some there was one sole cause, for others there were combinations of two or three. There was no obvious pattern across the group in that no single person or group of participants stood out as being different. In general there was a degree of consistency across the group and the causes put forward could be captured under four main headings: hereditary ("in the family"), linked with other atopic disorders ("genetic"), precipitated by an episode of RSV bronchiolitis or croup, or a response by the body to an external stimuli (dampness, immunisations, exposure to antibiotics in the womb).

These could be further seen as being either internal or external. Internal, reflected a sense in the transcripts that the child had a natural predisposition, was born with it, or inherited it through family genes. External, was reflected when asthma developed as a consequence of something that the child had been exposed to, e.g. a virus, antibiotics in the womb or dampness in the home. No mother described a single external cause. Examples of both categories follow. In mothers who attributed more than one cause they were often a combination of internal and external factors.

Internal Factors

These were commonly voiced as genetic or hereditary and expressed as: "born with it", "runs in the family", "family tendency", "the signs were all there". There was a keen awareness of the strong link between asthma and other atopic disorders such as eczema, hay fever and food allergies. Indeed as noted previously there was a high incidence of previous exposure to asthma and/or atopy within the mothers (seven mothers had asthma themselves). Therefore it was not surprising that in this group, and particularly in the mothers who also had atopy or asthma themselves, a positive family history of asthma and or atopy was seen as a dominant cause. Examples of how cause was expressed in the mothers' narratives follow.

Participant S4 who has asthma herself.

S4: "I think he was just born with asthma, I think it's probably a genetic predisposition that people have to asthma. I have asthma, I had severe asthma as a child, his Dad's family are all atopic they have eczema, and his Dad was always told that when he had a cold as a child it went into his… we think he was born with it, it's intrinsic to him".

And a mother who had eczema, and a brother with asthma.

S11: "With him being wheezy and with me having eczema that they two were linked. They said asthma and eczema's linked he could take one or other so with him being wheezy all the time and my brother's asthmatic also so it ran in the family sort of thing".

Combinations of internal and external

For some it was a combination of both internal and external. Participant S3 who did not have asthma had linked two of her children to developing asthma following chickenpox in early childhood, as well as there being a family tendency (the child's father has asthma as a child).

S3: "Okay I think she obviously has a family tendency, there's a hereditary, but I do believe there was something in chickenpox that maybe made her more vulnerable and maybe lead to her displaying symptoms of asthma at that time….because interestingly enough our eldest son, he's nearly nine and he had chickenpox when he was about one and a half and he was pretty ill after that and was in and out of the hospital with coughing and being sick. The hospital did lots of tests and said we've eliminated all these things the only thing we think it can be is asthma, and for a very short spell he had inhaler… So both of them after they had baby chickenpox displayed other symptoms of asthma and being sick".

Participant S7 had an older son with asthma and was concerned that exposure to dampness in the home had played a part. She also had ideas about vulnerability and a sense of an inherent weakness in the boy, linked to a possible failure of his immune system.

S7: "What causes the asthma, I think his problem is he cannot fight any virus, cannot fight it and that is the killer of him 90% of the time he goes from one virus to another constantly".

There was no consistent link in attributing cause with whether or not the mother had asthma. In some, the picture was complex. Participant 1 had developed asthma in adulthood, her son had first had Respiratory Syncytial Virus Bronchiolitis in infancy and she also suspected it may have been triggered by conditions surrounding his birth, with the boy having had a very low temperature and requiring warmth and oxygen.

One other mother participant S21 mentioned a link to conditions of birth.

S21: "There's other things I've read about when actual point of birth if it's a speedy delivery you can damage this part (back of head at neck level) of your neck this is Chinese beliefs actually and this is where your immune system is here so that might have damaged it and I was thinking he did have quite a speedy birth actually, so I was thinking that, you think of loads of things just trying to work it, I do think that something happened to trigger it off he had susceptibility, it was in the family and maybe I don't know I do have these beliefs but maybe I'm just talking rubbish maybe its the pollution".

The mothers could all identify a cause of asthma in their child. This was not unexpected because it is recognised that people seek an explanation for personal illness, commonly exploring issues around aetiology, pathophysiology, mode of onset, course of illness and treatment[105]. There is no a priori reason why a parent would not search in similar areas for an explanation of illness in their child. Indeed, there is a growing body of literature showing that parents of children with asthma strive to make sense of the illness in order to maintain family function and ordinariness[194;195]. This may be particularly important in a disease such as childhood asthma as much of the management is based in the home and is primarily the responsibility of the family.

The causes given by the mothers for their child's asthma sat comfortably with other qualitative studies of parents across different ethnic populations. If all

references to genetic, hereditary, or "in the family" causes in the Glasgow study were combined this would account for 76% of the group. Perception of aetiology in carers of children with asthma persistently rates 'hereditary' most highly. In Handelman's study 71% declared 'hereditary' as the principal cause[107], 59% in Rich's study of Navajo asthma families[108], and 60% in Peterson's African-American care-givers[106]. When compared to a Scottish population the mothers' explanations again fitted well with accounts of women interviewed by Blaxter in 1983[98].

The question is raised as to whether it is important that the parents have causal explanations for their child's symptoms. Adults who believe their asthma to be of 'internal causation' have shown better self-reported adherence with treatment regime[196]. If this was so for parents of children with asthma then it might be of practical help to ascertain parents' causal beliefs and explore adherence issues with those individuals identified as external, as parental compliance with asthma preventive treatment regimes is often poor. For example, one study showed that for a standard twice-daily regime of inhaled steroid almost one quarter of doses were missed[28].

The asthma models expressed by the mothers were consistent across the group, who represented a spectrum across Glasgow society, including those from areas of privilege to high deprivation [Table 2]. The complexity of models showed no obvious link with social class. These may be models specific to their experience and or geographical location. However with such consistency across the group and similarities with literature reports this was unlikely[108]. It is worth noting that current theory about the presence and treatment of inflammation in asthma was prominent in the mothers' descriptions.

Traditionally, views constructed by lay people (as in non-medically trained public) were expected to differ in accuracy from those held by health professionals[197]. Yet in keeping with other studies exploring asthma models in parents of children with asthma the models described in this study were factually accurate[107;108]. Similar to Handelman's study of female carers[107] (16 mothers and one grandmother with custody) in inner city Boston USA, the mothers in the Glasgow

study were able to correctly describe bronchoconstriction, inflammation, and resultant symptoms.

How representative of the public are the beliefs offered by the mothers in this study? Recently Shaw has argued against the existence of pure lay health beliefs[198]. He believes that through contact with health professionals and health services beliefs in lay people become modified. He describes them as being "filtered and adapted over time". From the evidence of an understanding of asthma as an inflammatory process, it is likely that this was what happened in the mothers in the present study. Within a person, beliefs about asthma are likely to change over time, and during a person's lifetime. Certainly a number of asthma studies have shown opposing views within families when comparing the child's perception of asthma elements to that of the parent[112;199]. This suggests that at some time between childhood and adulthood the beliefs may change, although exactly when or how is not known. This was confirmed in the study by Handelman, which included children and adults from the same families[107]. The children were shown to hold different ideas about the disease when contrasted with the parents.

In general, the group studied which were drawn from those attending a specialist asthma clinic / or paediatric hospital for asthma care were shown to hold ideas about asthma that were congruent with medical views about asthma. How their views were formed, and exactly when, was not known. Small references to sources of information on asthma were made which included books, health professionals, as well as the Internet and friends and family. These were consistent with methods that the general public searching information is likely to seek and access. Indeed, at the Royal Hospital for Sick Children in Glasgow providing an information book about asthma for parents is part of good clinical practice and is made widely available to families attending the emergency department and the wards. This was reflected in some of the responses from the mothers who had received it in the past.

S5: "I had a very good booklet given to me at the hospital "

S9: "The orange book mind I learnt a lot from that I still do"

S18: "The information they gave us up here the book and things"

Additionally individual health professionals had on occasion provided special verbal and written information.

> *S11: "I was young I didn't understand what they were talking about really, and hold on he was in [the hospital ward] and there was a really nice wee man he drew me a diagram and all that like, I'd questions: what is that's wrong with him and how's his breathing and a man he sat me down and explained and afore that, naebody actually, they just spoke to me I said Aye, Aye and I didn't really understand and it was that doctor that drew me the diagram and explained everything to me so I could understand it better, it was really helpful".*

Another mother said:

> *S12: "Well see that time I was in Spain I told you about it was like a private clinic we went to and when I took my daughter she was on Ventolin as well and myself this doctor there sat and drew out pictures for me of like your tubes, cut it across and he showed me. He drew a circle that's like cut across then he put in the inside bump bits and that's when it closed and the ventolin opens it. What I'll never forget is he said we don't actually use Ventolin because it only opens, it's not a preventative, it's only opening. So whenever I think of it I think of that picture that he drew".*

Lay conceptualisation developed for children

One imaginative adaptation of the mothers' model was noted. One young mother (participant S9) told how she used her model of asthma, the tube model, to develop a working scenario for explaining asthma episodes to her son. This mother had asthma and was particularly keen to impart as much knowledge to him as possible. It features the concept of the airways being taken over by an army of small men who compete for the air and take it away from the child.

> *S9: "Aye, it sounds mad but we telt him that when he's got asthma there's wee men in his chest, like his tube, and they're all in the way moving around and they keep the air away they push it up when he tries to breathe it in, and when he starts to feel bad he says his wee men are there". I drew a wee picture for him. Like two lines of a tube with lots of wee men in it. When he has an asthma attack when its coming on we say the wee men are there again. The men are out the wee holes they live in and they fill up the tube.*

When he tries to breathe in they block the air. Like the air comes down and the wee men keep pushing it back up again, its not getting down right. He knows his asthma medicines get rid of the wee men. When he feels his asthma coming on he says the wee men are there again, the wee men are in my chest".

This quote stood out from the others as being the most pure example of a lay description. It is unlikely that a health professional would impart such imagery. No other such examples were given.

Lay use of non-orthodox practices

In addition to information about asthma models the mothers talked about practices they employed when caring for their child with asthma. In previous chapters there has been evidence and discussion about the mothers use and understanding of conventional asthma treatment. In this section information around non-medical interventions that they participated in is presented.

The mothers talked freely about making use of additional non-conventional activities or treatments, making no effort to conceal the information from the interview. Mostly the information came entwined within the responses.

Complementary and Alternative Medicines (CAM) use

The mothers did not rely solely on conventional asthma medication. Six mothers told of either trying or using regularly treatments that were part of the CAM spectrum. These included; Calpol, cough bottles, essential oils, special diets, herbalism, homeopathy, Chinese medicine and breathing techniques. The CAM were used alongside the traditional asthma medication.

One mother described how she used Calpol (a liquid paracetamol preparation for children) and sometimes a cough bottle. She had a clear idea that the cough bottle was not approved of by the medical profession. She indicated that Calpol seemed appropriate for when "he's coming in for something". As most asthma exacerbations in young children are triggered by viral illness this did not seem an inappropriate response. This mother had asthma herself.

S8: "Well we give him some Calpol first because we think oh, he's coming in for something and he gets a cough bottle for his cough sometimes but he'll take the cough bottle, we try him with his asthma things his dad'll pin him back and give him some of that to see if it'll help a wee bit. But I think the screaming makes him worse so really the only we do is give him Calpol and cough bottle. The doctors don't give you cough bottles, they don't believe they work, so you've always got to go out and buy tixylix".

Not all the mothers interviewed were in favour of alternative approaches. Two mothers were particularly sceptical of alternative approaches. One, a young mum, had been told to try giving her child a type of iced lollipop to "cool the chest". She recounted the story of what happened when she did.

S11: "Somebody had said to me gie him icepoles, I was going out buying all these icepoles, keeping them in the fridge it cools his chest I thought that's got to be rubbish. I tried it but to me that was a lie I didn'y dae. I used to come up to the doctor and say I've been giving him icepoles and they were that way they looked at me and I felt what are they looking at"

Participant S4, a mother who had asthma, explained why she would not even try a common cough preparation because of its lack of any recognised asthma drugs. She described having debated this with her mother in law, who had suggested the over the counter cough medicine.

S4: "I wouldn't give him tixylix because I think it has no active ingredients so I wouldn't bother I wouldn't feel at all comfortable giving him txylix but I would by giving salbutamol".

Other approaches included sitting the child at an open window or taking her out into the tenement stairwell ("the close"). Participant S13 did this because on a previous occasion taking the child out of the flat and sitting her in the car ready to go to the hospital seemed to settle her. Thereafter she had adopted it as a possible strategy to try again.

S13: "I've had everything packed and I've taken her out into car and I've sat with her and the cold air and sitting her upright in the car seat and she's actually stopped and I've taken her back into the house... I've never actually had to I've just taken her outside and that seem to help her. I've

even taken her and just sat in the close with her at night with the window open, wrapped a big duvet round her had her sitting out there half asleep holding her".

Additionally a mother, participant S21, explained how she used steam, more commonly associated with the treatment of croup, as she pointed out.

S21:"He's always enjoyed listening to the shower, even now he lies down next to the shower since he's been a baby it calms him down he listens and he goes to sleep, so that kind of helped it, the steam I think it did help him a wee bit when he had croup"

[Interviewer] "How do you think that works then the steam?"

S21: "It must be sort of, like an inhalation because I would rub some Vicks on him as well and I suppose it must be I don't know"

In summary, there was some use of complementary approaches evident in the group. The mothers featured in this section included some with asthma as well as not. There was no obvious pattern seen between the two.

It is not unusual for CAM to be used alongside conventional treatment. Indeed, within the asthma population and carers CAM use is known to be high[200;201]. CAM use within the UK for asthma is gaining popularity. In a recent English study regarding access to information about CAM therapy within the NHS 62% of the study group stated they were using complimentary therapies for asthma. The group included adults with asthma and parents of children with asthma[202]. In this study 29% of mothers described trying or using a CAM, alongside conventional asthma therapy. These included essential oils, herbal creams and brews, vitamins, Chinese medicine, and attending a well known alternative nutritionist. There was a sense that they wanted as much as possible to be "natural". A further three mothers expressed an interest in trying alternative options such as attending a Homoeopathist and Herbalist. The 29% reported use in this study compares similarly to the amounts described in the Handelman study; where 35% used herbal treatments, 35% breathing techniques including steam, and 29% religious healing.

Does CAM use tell us anything about development of self-regulation in the mothers? In the Zimmerman model parents are disadvantaged if they hold health beliefs that diverge from the orthodox medical views about asthma that are incorporated in the model. For example, relying on over the counter treatments to treat asthma or believing that restricting activity would limit symptoms was used as a criterion for failure to progress in self-regulation development and was characterised as Phase 1 activity. In this sense the Zimmerman model follows what could be described as a strictly medical model for management of asthma. In the original Zimmerman article, the authors made the point that so few subjects had reached full self-regulatory status despite attending a major hospital centre, implying that, by attending a specialist medical centre, parents might adopt health beliefs that may differ from their own[85]. In reality it seems more likely that the two (orthodox and non-orthodox treatments) can co-exist.

Mothers with asthma: The 'by proxy effect'

Participants for the current study were not selected on the basis of a personal history of asthma, however seven mothers had asthma themselves [Table 2]. It was not known initially whether this would have any effect on their management of their child's asthma. Participants were asked about a personal family history of asthma and atopy before the interview commenced. ParticipantS1 revealed she had developed asthma herself later in adulthood but nothing said in her interview suggested this had influenced her asthma behaviours for her child.

The possibility of a 'by proxy in a mother with asthma' effect was raised in the fourth interview with participant S4. Whilst being asked about her confidence in asthma medication she revealed that she had different ideas about compliance between herself and when it came to her child.

> *S4: "I'm not very good at long-term things I'm not very good at complying with long-term therapy, not for my children but for myself unless I can see a benefit quite quickly I'm quite lazy about waiting for effect".*

As participant recruitment progressed five further participants who had asthma themselves were recruited. In these interviews particular attention was paid to signs that this may have affected their development or in any way made them

different to the rest of the sample. The interview guide was not altered to specifically pursue this line of inquiry.

On completion of the study seven mothers, who had asthma themselves, had been recruited, participants S1, S4, S6, S8, S9, S12, and S14. No striking differences in their self-regulatory behaviour were seen between them and the main group. The idea of doing something differently was raised occasionally but not in any way that indicated any significant difference. An example of how a difference was expressed is given next:

> *S14: "Yeah I think I can because I've never been very, I've always taken my distance to the whole medic thing, I mean I gave birth at home to my children, I tried at least and I hated that I had to go up to the hospital I was yeah really kept my distance of this whole thing which I can't do now so that has definitely changed".*

In summary, the mothers who had asthma remarked on the following things they specifically did differently when acting on behalf of their child as opposed to themselves:

1. Adhered to preventive treatment regimes
2. Avoided cigarette smoke
3. Had contact medical services, whereas before she avoided
4. Passed on to the child as much information as possible

However, there was no evidence that their parental asthma management practices differed from the rest of the group. It is not known if in a larger sample of parents with asthma this would be any different.

Discussion

There exists a degree of uncertainty in the literature around exactly where and how beliefs might influence parental self-regulation of asthma. In Leventhal's model of self-regulation decisions to follow medical advice are influenced by an adult's beliefs about the nature, cause, and consequences of an illness[203]. Weinman et al (in studies which included adults with asthma) have linked illness representations, which include a person's beliefs about aspects of their illness,

with health-promoting behaviours[80;94]. However, in her work on self-regulation activity in parents of children with asthma, Clark showed that use of elements of the self-regulation model (observe, judge, react) were unrelated to parental health beliefs[67]. Thus, there is a lack of consensus about the role that beliefs about asthma play in development of self-regulation.

It was important therefore to examine the lay models held by the mothers to look for any signs of divergence that might explain failure to develop self-regulatory behaviour. No such evidence was found. The results in this study showed that the mothers held models of asthma congruent to biomedical models. Some mothers used some non-orthodox approaches, but they were used in tandem, not in preference of orthodox asthma treatments. In this sense this chapter confirms findings in the previous chapter where the mothers were seen to react to early signs of asthma exacerbations and treat with conventional asthma medication.

In the self-regulation literature Demetriou hypothesised that to be considered capable of self-regulation a person must posses the capability for (a) self-monitoring, (b) maintaining an organised state of self-representations, and (c) self-modification of skills and implementation of strategies[179]. If his criteria were applied to self-regulation by proxy they would become (a) the capability for monitoring the child ("vigilance"), (b) developing an organised state of illness representations of asthma, e.g. lay models of asthma, and (c) the ability to develop a range of modification skills and strategies. Further, if these were seen as essential ingredients for becoming self-regulatory then the mothers in the current study are clearly in the process of developing appropriate skills. Vigilance corresponds well to child-monitoring skills and the personal lay models of asthma function as *illness* representations.

Respect for the lay voice in health care varies. In 1981 Blumhagen noted that a clinician who knows the contradictory beliefs held by the patient is more effective than the one who knows nothing about how the patient experiences illness[105]. Implying that understanding the lay voice is an essential pre-requisite for effective clinical practice. In 1998, within a research context, Popay linked quality of health service research to its ability to privilege subjective lay behaviour and accounts[148]. Suggesting policy and practice developments based on evidence

which ignores the lay voice would be of poor quality and unlikely to lead to successful change. More recently in the self-regulation literature Bandura reflected that too much attention was devoted to the development and predictive value of self-regulation theories yet surprisingly little to their social utility[83].

> "The benefit from the science of self-regulation will rest heavily on its social utility".

One way of interpreting what Bandura meant is that a model for self-regulation would be most successful if it fits the wide spectrum of beliefs held by the target population. In this sense understanding explanatory models that mothers use to make sense of their child's asthma would allow developmental models and future health interventions to be culturally relevant and sensitive to the views and beliefs held by mothers. The mothers in this study had models congruent with biomedical models suggesting that asthma interventions for parents of young children based on the traditional biomedical model would be recognised and understood. This raises the question of why so few studies targeting parents of young children lead to improved health outcomes. One suspects the answer might lie with interventions failing to recognise the practical challenges that confront mothers of young children with asthma at this time, rather than having been designed around the wrong theoretical content.

Summary

The basic foundation model for the mothers' asthma behaviour is the mothers' explanatory model for the disease itself. It is likely that the model of asthma developed quite early on in the asthma experience. The models the mothers held were accurate and generally convergent with current biomedical understanding of asthma. There was no evidence that their beliefs had interfered negatively with their development of mindful self-regulation.

The next chapter describes measures of triangulation that were employed in the study to add validity and reliability to the qualitative interview data.

CHAPTER 8. TRIANGULATION

This chapter describes the theoretical reasoning underpinning the use of four questionnaires measuring Coping[204], Illness Perception[80;93], Conscientiousness[205] and Personality[206;207]. It also details how the chosen instruments were administered, as well as the results and interpretation of the data.

Introduction

Triangulation is the application of several different research methodologies in the search for the same underlying phenomenon to extend the amount or type of information collected[129;130;132;140]. By combining qualitative and quantitative methods, the researcher can potentially overcome any weaknesses or bias that might arise from single-methods. Triangulation may also be used to confirm findings through the convergence of different research perspectives, and as a means to check reliability and validity of the results. Different methods do not necessarily produce different versions or levels of answers rather they help to establish the overall picture.

This chapter describes additional measures that were taken to enhance the reliability and validity of the qualitative interview results reported in the previous chapters. As described in the Methodology chapter (see Strengthening Qualitative Research section) key points from published reports were used to strengthen rigour and validity around the qualitative data collection and sampling[137;148-150;208]. Using more than one method of data collection was particularly important in this study because tools to investigate the development of self-regulation were limited, and the principal qualitative method was a single interview, delivered by a single researcher. It was therefore decided that a form of triangulation was necessary and would be developed in order to cross check the theoretical interpretations from the qualitative interview.

In the literature, it is recommended that the intention of triangulation in a study be clearly stated as either for confirmation or completeness[129]. Accordingly in this study the purpose of triangulation was to act as confirmation of the interpretation of the qualitative data set.

Reliability

Reliability refers to the accuracy of research methods and techniques, and the extent to which results are consistent over time and/or give an accurate picture of the total population under study[129;130;149]. It is concerned with whether the way of taking a measurement will tend to produce the same result upon repeated administrations. In this study, measurement (the interview) was only done at one point in time for each participant. Therefore, reliability could only be provided in the means of standardising delivery of the interview and the questionnaires. As described in the previous methodology chapter stringent efforts were undertaken by the researcher to ensure that the interviews and data analysis were undertaken in a similar manner with every participant.

Validity

Validity refers to whether the research truly measures what is intended[130;140]. In the qualitative interview the findings were seen to relate directly to the study aims and to the known theoretical understanding of self-regulation. In this chapter, thought was given as to how the oral testimonies of mothers could be measured against written, more objective accounts of themselves, their experiences and their personal development[149]. Additionally, the constructs under investigation in this section were assessed by validated questionnaires and were administered in a way, which could be easily replicated by others.

Combining findings

Whilst the integration of more than one method of study can be highly productive, corroborating findings from more than one source is not straightforward[140]. Particular attention must be spent on considering how to link different levels of findings toward a common level of explanation. When selecting methods of triangulation, Mason suggests that the researcher first assess whether the two sets of data will indeed yield information about the same phenomenon and whether both methods will yield comparable data[140].

In the current study prior to selection of additional methodology the following two questions were considered:

1. Would they (i.e. the qualitative interview + other results) tell about the same phenomenon?
2. Would they (i.e. the qualitative interview + other results) yield comparable data?

1. Would they tell about the same phenomenon?

With the exception of the Zimmerman Self-Regulatory Development Interview Questionnaire, there are no validated tools to specifically explore the development of self-regulation in mothers of children with asthma. However, a review of the theory, describing different conceptual models of self-regulation, suggested that exploring coping and illness representations in tandem might be worthwhile[81;209-211].

Coping

Coping has considerable overlap with self-regulation as both involve adapting to change[212]. At its simplest level, coping represents an individual's response to a change in situation or a perceived threat[213]. Similarly, self-regulation represents a process through which individuals use self-generated thoughts, feelings and actions to overcome a threat or block to attaining a personal goal[67;71;84;214]. Thus both coping and self-regulation contain elements of responding to a change in situation in order to retain, or progress to, a desired state of equilibrium. The processes employed in goal acquisition, the premise on which self-regulation sits, are very similar to those activated when responding to a serious threat as seen in coping. Indeed, Leventhal's model of self-regulation names coping as the second stage of his cyclical process of interpretation, coping and appraisal[203]. Coping allows people to use various skills to manage problems or stressful situations they encounter. In health, active versus avoidant coping strategies have been associated with improved health outcomes[215;216].

In the current study, an assessment of the mothers' coping was decided upon for two reasons. First, in practical terms, it was relatively easy to assess, with a number of easy-to-administer validated questionnaires[204]. Secondly, it was felt to be important to observe any similarities that might be present between the two processes. Thus inquiry about coping might help expand understanding around how self-regulation might develop.

Illness Representations

As seen in the Introduction illness representations have also been closely linked to self-regulation[94;209]. In Leventhal's self-regulation model the representation or beliefs an individual holds about their illness is seen as an important influence on their behaviour and appraisal of its efficacy[203;210]. Therefore study of illness representations is based on the theory that patients' illness representations, also known as illness perceptions, will predicate their behaviour.

Representations of illness are a person's own implicit common-sense beliefs about their illness[203]. People use them to make sense of their illness. They are based on five distinct components: identity, cause, time-line, consequences of illness, and beliefs about cure and controllability of the condition[217;218]. Illness representations have become important in health care research because they have been shown to provide a framework through which people perceive and manage illness[211]. For example, a belief that an illness is serious may enhance perception and awareness of the symptoms, which may in turn increase the sense of effect on functioning. Representations may also interact with adherence to treatment regimes[92]. The Zimmerman model also works on the premise that to progress to a fully self-regulatory status, a parent must adopt a belief that asthma is a chronic long-term illness[85]. Therefore, it seemed appropriate to assess such a phenomenon.

Conscientiousness and Personality

Much less is known about how self-regulation interacts with other constructs such as conscientiousness and personality. In a comprehensive review of self-regulation, Zeidner highlighted such interaction as an important area for research[219]. Personality and conscientiousness might be important because of their known link with disease management behaviours.

Personality was explored because of the known links between personality, illness, and health[220;221]. It may also be important when establishing rapport (with health professionals) and for selecting the optimal form of treatment[222]. For example more extrovert people may be more likely to engage in a working partnership with a health professional. Neuroticism, one of the constructs of personality, has been linked with depression. Depression has been linked to poor

outcome and adherence to treatment in adults with asthma[223]. It was not known if this is the same for adult carers. Neuroticism is known to be a predictor of less good outcome and coping because it is linked with lower levels of success at dealing with stressful situations, a generally less positive outlook on life and lower levels of well-being[207;224]. All these factors might then have implications for how parents manage their children's asthma.

Conscientiousness is a dimension that includes such traits as perseverance, reliability, self-discipline and good organisational skills[205]. It is known to be related to health behaviour with higher levels of conscientiousness being associated with health-protective behaviours[225;226]. For example, in smoking cessation programmes, persons with high conscientiousness will be more likely to engage with quit measures[227]. For asthma, high levels of organisation, such as those associated with conscientiousness, are thought to increase adherence with medication[13]. In the educational setting conscientiousness is positively associated with academic and vocational success and self-regulation[84].

In the current study, it was decided to explore whether individual differences in conscientiousness and personality were related in any way to the mothers' asthma management style.

2. Would they yield comparable data?

After careful consideration, it was decided that questionnaires to measure Coping, Illness perception, Conscientiousness and Personality would be included. On a practical level, before conducting the interviews, it was not known if the interview data would be compatible for comparison with the questionnaire data. In the first interview with participant S1, the transcript confirmed that the interview prompt questions had indeed stimulated narrative around the severity of the child's illness, notions about longevity of the illness, and there were signs that the mother actively intervened in the course of asthma episodes. She also displayed organisational skills referring to the keeping of written records about her child's asthma, which she could use in discussions with health professionals, when attending a clinic appointment. At this early stage, it seemed that data relating to areas of common interest could be collected both by interview and questionnaire.

Descriptions of the questionnaires and how they were administered and processed follows.

The Questionnaires

COPE

The COPE questionnaire[204] [Appendix13] was selected to assess coping because it allows analysis of individual coping items, rather than just the traditional 'active' or 'emotion'-based coping. The individual items include: active coping, planning, seeking instrumental social support, seeking emotional social support, suppression of competing activities, turning to religion, positive re-interpretation and growth, restraint coping, acceptance, focus on venting of emotions, denial, mental disengagement, behavioural disengagement, alcohol and/or drug use, and humour.

There are two versions of COPE, a situational and a dispositional version. The dispositional version of COPE was selected to measure coping as it assesses an individual's general way of coping with a variety of encounters. It was thought the dispositional version was most appropriate given that the mothers themselves did not have the asthma, and this would relate most closely to their 'by proxy' situation.

In the dispositional version, respondents are asked how they respond when they confront difficult or stressful events in their lives. Looking at a wider range of coping skills is important as it had been previously assumed that an individual adopted one 'fixed' method of coping and used it continuously. With further research, it has been shown that individuals may use a number of coping styles for one illness. For example, work by Cohen et al showed that individuals with rheumatoid arthritis used one coping strategy for pain and another for threats to self-esteem[228]. COPE has been well validated and used in a range of chronic illness studies including irritable bowel syndrome[229] and diabetes mellitus[230].

The questionnaire consists of 60 items, which relate to 15 scales (i.e. 4 items per scale). The respondent is asked to rate the items on a 4-point scale from '1'- *I don't usually do this at all* to '4'- *I usually do this a lot.* Total scores for each scale

are computed by summing the scores from the four component items. The higher the score for each scale the greater the extent to which the coping style is employed. It is relatively easy to complete, taking about 10 minutes. It comes with an easy-to-use coding frame, which facilitates transcription into a database.

Illness Perception Questionnaire (IPQ) Carers Version

The Illness Perception Questionnaire (IPQ) [Appendix 14] was selected for measuring the mothers' cognitive representations of illness[80;93]. The IPQ has its theoretical origins in the work of Leventhal and his self-regulation framework[203;209]. Weinman and colleagues developed the IPQ in an attempt to further understand the nature of illness related behaviour[80;93]. The IPQ was designed to provide a robust assessment tool that could be used across illness groups and would provide a basis for developing interventions to enhance self-management behaviour in chronic illness. The original IPQ had items across 5 scales. The revised IPQ has items across seven scales, and in this version includes an assessment of the emotional representations[93].

The IPQ was selected because of its links back to self-regulation theory and the original validating studies included asthma patients, and the questionnaire can be easily adapted to create what the authors call a 'Significant Other/Carers Version'[231]. This version was made available through personal communication with Professor John Weinman, one of the questionnaire originators. The layout is identical to the patient version except that the wording is changed from "my illness" to "My child's illness", using the search and replace option in Word.

The Illness Perception Questionnaire has 38 items on seven scales (Timeline - 6 items, consequences - 6 items, personal control - 6 items, treatment control - 5 items, illness coherence - 5 items, timeline cyclical - 4 items and emotional representations - 6 items). They are presented in mixed order and are rated by the respondent on a 5-point Likert scale from '1' Strongly disagree to '5' Strongly agree. The total score for each scale is summed and then divided by the number of items.

Lower scores indicate fewer reported consequences of a child's asthma, weaker cure/control beliefs and a short timeline while higher scores represent serious

consequences, stronger cure/control beliefs and a longer timeline. The cause component is measured differently, as each of the eighteen causal items represent a specific causal belief. Half of the eighteen items relate to internal causal factors, e.g. 'my child's mental attitude caused his/her asthma', and the remainder to external causal factors, e.g. 'pollution in the environment caused my child's asthma'.

C-Scale

There are two popular scales for measuring conscientiousness: The Goldberg[232] and NEO-5[205]. In the current study, the conscientiousness scale of NEO-5 [Appendix 15] was selected for use because it can be easily administered, and it has been used when investigating the role of conscientiousness in health behaviours[227;233]. The C-scale of the NEO Five-Factor Inventory Profile consists of 12 items (consisting of statements), which respondents are to rate on a 5-point scale from 'SD' strongly disagree to 'SA' strongly agree. The scores for the 12 items are summed to create one overall score. Low scores indicate low levels of conscientiousness.

Eynseck Personality Questionnaire-Revised (EPQ-R)

There are two well-known questionnaires for assessing personality, NEO5[205] and the Eynseck Personality Questionnaire-Revised (EPQ-R)[206]. The EPQ-R was chosen to establish the role that the individual differences in personality play in mothers' management style because it has been well validated in chronic illness, specifically cancer, coronary heart disease and pain[234] [Appendix 16]. It is easy to complete, and has been tested on adults with different levels of education ranging from high school to further education level. The EPQ-R consists of 48 items (12 items per sub-scale) and measures three dimensions of personality; Extraversion (E), Neuroticism (N), and Psychoticism (P), and includes a Lie (L) scale. Respondents are asked to circle 'yes' or 'no' for each item and responses for each item are scored out of a maximum of 12. A high score on a particular sub-scale indicates that the dimension is highly descriptive of the individual.

Delivery of the questionnaires

The mothers always completed the questionnaires after the qualitative interview. The decision to have the questionnaires completed after the interview was informed by two concerns. The researcher was concerned not to let mothers get distracted with issues arising from the questionnaires. Further, it was judged that asking mothers to spend fifteen to twenty minutes completing questionnaires early in the visit would interrupt the development of rapport. Completing the questionnaires after the interview worked well in practice.

For the three mothers who chose to be interviewed by telephone the following procedure was put in place. The questionnaires were sent out first class the day before the interview. Usually, they arrived the same day of the interview. The mothers were asked to complete them after the interview. A stamped addressed envelope was provided for them to return the questionnaires to the researcher. All three sets of questionnaires were completed and returned. They were treated no differently than the other eighteen.

Coding of the questionnaire

The participants' questionnaires were coded following the interview and then put aside. For each of the questionnaires, a score was calculated for the individual items according to the originator's instructions. The scores were then entered into a Minitab database for anonymity and later comparison with the final qualitative interview analysis themes. This ensured the questionnaire data was not available to the researcher and could not influence the qualitative interview data analysis.

Results

COPE

Across the group the highest scores were seen on active coping (Mean 13.0, SD 2.20), planning (Mean 12.7, SD 2.66), and positive re-interpretation and growth (Mean 13.1, SD 2.60) [Table 4]. In general these would be seen as 'positive coping' measures. The lowest scores were seen on alcohol and/or drug use (Mean 4.6, SD 1.71), behavioural disengagement (Mean 5.95, SD 2.24), and denial (Mean 5.47, SD 1.83).

In general, the mothers showed dominance in the use of positive coping strategies. It was seen from the qualitative interview analysis that the mothers responded to signs of illness in their child by seeking an explanation, often from a local General Practitioner. This could be related to the 'active coping' construct in that they did not choose to do nothing. They actively acknowledged that something was wrong and sought to find an explanation. Indeed, there was no suggestion that they underplayed or underestimated the importance of what they saw, as confirmed with the low scores on mental disengagement and denial. The high recorded use of planning and positive reinterpretation and growth as a strategy used regularly accords with the mothers' reports of trying to plan ahead to avert asthma episodes at an early stage, and in their reports of learning by experience, building up strategies highlighted in the narratives of the mothers who developed incrementally.

The theoretical model of coping that the mothers seemed to follow most closely in this study is that of Taylor[235]. In that model, coping comprises of three processes, which are described as: a) a search for meaning b) a search for mastery and c) a process of self-enhancement.

IPQ

In the qualitative interview study, the common qualitative factors linked to self-regulatory progress in both incremental and instant groups were:

5. Taking the asthma seriously
6. Recognising the importance of giving the preventive medication
7. Actively taking responsibility or control from the health professionals
8. Increased confidence in altering the course of the disease (in relation to keeping the child well month to month rather than life-long)

The IPQ results were examined to see if any similar relationship were observed. In the qualitative interview, there was evidence that the mothers took their child's asthma seriously, with 71% stating this openly during the interview. The IPQ does not directly measure 'seriousness'. The closest item for comparison is 'consequences' which is said to reflect the degree to which the illness has serious consequences for the carer. The participants had a mean score on

'consequences' of 3.2 [Median 3.3, Range 1.8-4.3, SD 0.69], which reflected a mid level score. In the IPQ, 1 is low and 5 high [Table 4].
In this study, the highest scores the mothers achieved on the Illness Perception Questionnaire were seen on treatment control (Mean 3.9, Median 4.2, Range 3.0-5.0, SD 0.51), personal control (Mean 3.8, Median 4, Range 2.3-4.8, SD 0.14) and timeline cyclical (Mean 3.6, Median 4.0, Range 2.7-4.7, SD 0.56). This suggested that the mothers had strong beliefs in the treatment they were using, and in their degree of personal control in their child's asthma. The longer timeline is in keeping with a perception that this was not a transient illness.

The three items supported key findings in the interview data. Firstly, the interview data showed that 100% of mothers acknowledged the important role that preventive treatment in the form of inhaled steroids played in controlling their child's asthma on a day-to-day basis, and the strong emphasis they put on being able to take control of their child's asthma from the health professionals.

Secondly, while the mothers hoped the asthma might recede in time, they displayed a strong appreciation of possible genetic or inherited links.

The lowest scores were seen on illness coherence (Mean 1.9, Median 2.0, Range 0.8-3.2, SD 0.67). The illness coherence item relates to the mothers' coherent understanding of her child's asthma. This is thought to reflect the way the individual evaluates the usefulness of the illness representation. The results from the questionnaires suggest the mothers did not find illness representation useful.

C-Scale

Scores for this scale ranged from 26-40, with a mean of 33.1 (SD 4.86) [Table 4]. A highest score of 40 was recorded by participant S13, and the lowest score of 26 by participant S10. In this study, the levels were seen to be average. A slightly lower level of conscientiousness was seen between the mothers when split into incremental and instant groups but given such small numbers in the instant group this is unlikely to be of any great significance.

Incremental (N=16) Mean 33.1, Median 33.5, Range 26-40, SD 4.8

Instant (N=5)	Mean 31.7, Median 30.5, Range 26-40, SD 6.5

EPQ

The higher the score on a given scale (P, E, and N), the greater that the trait in question will influence the person's thoughts and behaviours. In the present sample, the mean scores were largely similar to the norms for women of a similar age, with the exception of scores on Extraversion where the sample mean of 10.1 (SD 2.5) is substantially higher than the normative mean of 7.5 (SD 3.00)[206] [Table 4]. The difference may reflect the fact that those who volunteer to take part in research studies will often tend to be more out-going individuals. The fact that the "Lie scale" mean of 4.5 (SD 2.0) was rather higher than the norm of 2.8 (SD 2.4)[206] does not necessarily indicate that the women in the sample were less honest in their responses, but merely that they wished to present themselves in a socially-acceptable light.

Analysis

Because of the small numbers in the study there had been no intention to subject the data to statistical analysis. There were no links or trends seen between any of the measures and indices of deprivation.

Discussion

The questionnaires were used primarily to add validity to the qualitative interview findings. They are largely descriptive because of the small sample size, and were never intended to be subjected to statistical testing.

Did they add validity?

The questionnaire, which offered the best direct comparison to interview data, was the Illness Perception Questionnaire. This provided a quantitative assessment of the components of cognitive illness representations. The sample means for each item were comparable with reports of adults with chronic illness (Rheumatoid arthritis, Chronic Fatigue Syndrome and Irritable Bowel Syndrome)[229;233;236]. There are, however, no published data for mothers of children with asthma with the IPQ with which to compare.

The illness was seen to have moderately serious consequences with might lead to expect a longer time-line accordingly. The illness perception questionnaire reflected most closely the key findings of the qualitative study. Because of that it might prove particularly useful in clinical practice. It is relatively easy to complete and analyse.

The results of the conscientiousness and personality assessments confirmed a group of participants within normal ranges for the measures of personality and conscientiousness[205;206;222].

Summary

The questionnaires proved easy to complete for the mothers and to interpret. The intention of administering the questionnaires was to use them to confirm findings derived through qualitative investigation. The Illness Perception Questionnaire proved most useful. None of the other items provided any insight into the mothers' pathway to self-regulation. Neither was route to regulation linked at all to a particular type of person. Whether this relates solely to the small sample size is not known.

What emerged clearly from the findings presented here was the important role the Illness Perception Questionnaire played in highlighting factors affecting the mothers' self-regulatory development. Therefore, as well as using it for developing interventions to enhance self-management behaviour, as Weinman et al originally intended[80], it should be considered a good alternative to an in-depth qualitative investigation of carers' self-regulatory development. Hereby extending its usefulness in further research of disease management theory.

CHAPTER 9. CONCLUSION

The preceding chapters described the experiences of a group of mothers when confronting asthma developing in their children and their progress in developing asthma self-regulation skills. This final chapter draws together the findings in relation to the research aims set at the start of the study and sets this in the context of what is currently known about self-regulation. It also highlights some implications for clinical practice.

To recap the study aims focused on three areas;

1. Exploration of the initial emergence of asthma, in particular the conditions present and the diagnosis.
2. Any evidence of the development of self-regulatory skills, and factors associated with development and use.
3. The behavioural influence of beliefs held by the mothers about asthma, and how they related to known models of asthma.

The aims of the study were fully realised. Particular attention was paid to ensure that the lay knowledge and descriptions provided by the mothers were given prominence and represented clearly. The findings contribute to our understanding of the development of self-regulation in mothers of young children with asthma and have implications for clinical asthma practice.

The most important findings are highlighted in this final discussion.

Initial presentation of asthma

The mothers were very forthcoming with information around the initial presentation of asthma in their children. For most, this was a negative experience. It was a time associated with significant uncertainty due to the diagnostic delay. This delay occurred despite the presence of markers such as a high level of associated atopic illness in the children and their parents, which might have been expected to alert the clinicians.

Such situations are not unique and have been well reported[53;54;111]. What is disappointing is that they persist despite advances in understanding of asthma and its presentation in young children. Frequent wheezing episodes in the first three years of life plus a parental history of asthma or eczema increase the likelihood of having active asthma between the ages of 6-13 years[237]. Such conditions were present in many of the children in this study and could have provided useful markers facilitating an earlier diagnosis of asthma had they been recognised.

What was striking in the mothers' narratives was the degree of observational skill they displayed. Through their observational skills and alertness ("vigilance") they were quickly able to spot asthma developing in their child. Vigilance has two important roles. Firstly, it has been highlighted in the literature as an important step for parents in gaining control and achieving a control when confronted by the emergence of a chronic condition in their child[115;175;176;178;238]. Secondly, Vigilance relates strongly to the observational sub-process of the self-regulation cycle and is critical for regulation to take place[67;76;77;79;81].

Current understanding of self-regulation theory

There are almost no specific studies of self-regulatory development in mothers of young children. The majority of published studies have included young children within a study population of a wider age range[57;67;85;91;122].

The findings accord with current knowledge of the activities involved in the self-regulation model and the constituent process parts of observation, judgment and reaction. The self-regulatory activities described by the mothers are comparable with the processes described by Bandura[71;81], Zimmerman[84] and Clark[67;239] ranging from mothers engaging in observational activity, to making judgements about intervening with appropriate management strategies and, assessing whether their intervention had been successful. Because their observational skills were so striking in the present study, and were clearly in place before asthma emerged, it suggests that mothers would be particularly well placed to benefit from targeted self-regulation skill training having natural skills in observation already in place.

The findings of the present study also concur with those of Zimmerman in that the mothers did indeed show signs of progression in their development of self-regulation skills. An unexpected finding was that not everyone developed these skills incrementally with some showing evidence of sudden advances. Irrespective of how their development had progressed, this group of mothers had reached a point where they were actively engaged in using self-regulatory processes to drive the management of their child's asthma. Further confirmation that the mothers were indeed operating at a sophisticated behavioural level is underlined by their reaching a state of 'mindful self-regulation'. They were not simply 'going through the motions' but had clearly grasped underlying principles. Clark has noted that such behaviour provides a useful demarcation between someone who simply uses self-management practices versus someone who self-regulates[239]. Underpinning the mothers' activities was a sense of growing confidence in their ability to alter the short-term course of their child's illness through engaging in the management strategies they had developed.

There are further parallels with the theory of self-regulation. Bandura believed that behaviour maintenance was the function of two variables; an outcome expectancy which related to whether or not a given behaviour would lead to a specific outcome, and an expectation about one's ability to engage in the behaviour (self-efficacy)[71;81]. The mothers, through their development and sense of self-efficacy had become able to intervene early in episodes with targeted asthma treatment and hence avert a forthcoming asthma crisis.

There was no evidence that the beliefs held by the mothers inhibited their self-regulatory development. On the contrary, the beliefs acknowledging the seriousness of the child's asthma were seen to enhance the likelihood of adopting self-regulatory behaviour. Although the study did not monitor compliance the fact that the mothers were seen to take asthma so seriously, and were so clear on the need for preventive treatment bodes well for adherence to the prescribed treatment.

Limitations of the study

Every effort was made by the researcher to conduct the study with a high degree of thoroughness and methodological rigour. Particular attention was paid to addressing standards that have been developed for ensuring the quality of qualitative studies[137;137;148-150;208]. Nevertheless, a number of potential limitations should be acknowledged, particularly in regard to the sample and the characteristics of the mothers who took part. These are discussed in light of the contribution that the study findings make toward the greater understanding of the development of self-regulation in mothers of young children with asthma.

Characteristics of the Sample

In qualitative research, sampling is based on adequacy and appropriateness[129;130;136]. In this study, sampling was directed by the tenets of grounded theory, namely that participants be selected primarily for their contribution to the emergent themes, and not, for their representativeness of the population from which they are drawn[138;139].

Initial study entry criteria were defined (the child was aged between 1-5 years, had a documented medical diagnosis of asthma, and a history of previous obstructive respiratory symptoms, was prescribed asthma prophylaxis and was not taking part in another research study) and all of the children of mothers in the study fulfilled the initial criteria. The criteria were relevant to the research questions posed and the phenomenon under study. However, whilst every effort was made to ensure the mothers represented a broad range from across society, the complete sample was seen to have certain characteristics:

1. All of the mothers sampled were attending a children's hospital for specialist asthma care.
2. The majority of the mothers were over 30 years of age.
3. The majority of mothers were married or co-habiting.
4. There was a high degree of previous exposure to asthma and associated atopic illness (namely eczema, allergy and hay fever). Indeed 7/21 mothers had asthma themselves.

Each of the above characteristics is discussed in further detail to allow speculation as to how they might affect interpretation of the results and applicability of the study to the wider group of mothers of children who have asthma.

Contact with specialist service

This was a hospital-based study and, as such, the mothers selected were all attending a children's hospital for specialist asthma care for their child. Whilst much of their early exposure to asthma occurred while under community medical care, there was no comparison available with a similar group of mothers who had not yet had access to specialist asthma services and care. The fact the children of the mothers recruited in this study were attending hospital raises the likelihood that they represent a group of children with more severe asthma. It is known that despite the large number of children attending hospital for asthma care, they represent a small proportion of children with asthma in the local community[119;240]. It is possible that the severity of the children's asthma may have influenced the mothers' experience and self-regulatory development. In order to test this phenomenon, it would require a study including a community based sample that had never been to hospital to see if the same issues were present, as well as to investigate whether the picture of developing childhood asthma was similar in the community.

Age

Of the mother

No attempt was made to select the mothers by age, but it was noticeable that they were largely a group of more mature women, with a median age of 35 years (Mean 35.4 years, Range 21.2-46.7, SD 6.4). Whilst this reflects the trend toward women having children later in life, it is higher than the national Scottish average of mothers' birth-age of 29 years for 2005[241]. One explanation for this may be that theoretical sampling latterly focussed selection on mothers who exhibited a degree of mastery, as perceived by health professionals based at the hospital. This may have unwittingly identified a group biased in terms of how well they were perceived to be doing. Maturity may have been mistaken for mastery. There

were, however, exceptions; two of the youngest mothers in the study showed exceptional awareness of their children's asthma.

Of the child

The children in this study were young, being all under five years of age. This was a deliberate decision in order to explore "self-regulation" in its purest form where the mother as carer was acting 100% on behalf of the child. It is possible that asthma developing in a school-age child may have a different course, perhaps avoiding the early diagnostic difficulties noted in younger children and creating a totally different set of circumstances for a mother. For example, it is possible that the diagnostic difficulties encountered in this group of mothers may not exist in children presenting with asthma for the first time at an older age. Although asthma commonly starts in the early years of childhood, this is not invariable. What effect an earlier diagnosis would have on the development of self-regulation skills is not known.

Relationship status

The majority of mothers in this study (19/21) were all in relationships and were living with a male partner. Only two mothers could be classified as young lone parents (participants S9 and S11), and one of those was living in her family home with her own parents and other siblings. The other lived close to her mother and father and made specific reference in her interview to how much they had helped and were involved in her child's day-to-day life.

The availability of social support, including the daily support and presence of a significant other, has been suggested, although not proven, as a factor of importance on chronic illness self-management[242]. A recent comprehensive review, which included asthma, showed support for a modest positive relationship between social support (i.e. the more the better) and chronic illness self-management[243]. It is possible that a group of mothers in a different social situation may have had a different self-regulatory development journey. In this study, it was not a theme that emerged spontaneously as of importance in the interviews. However, it should be acknowledged that there was no specific exploration of the role that a supportive relationship might play in the development of self-regulation

Previous exposure to asthma and related atopy

In general, the group interviewed had an exceptionally high prevalence of asthma and related atopic illness within the family, either in themselves or in their partners and children [Table 2]. Indeed, only four of the twenty-one mothers in this study had no medical history of asthma or atopy themselves or in their partners or other children.

Generally, it is recognised that atopy is an important driving factor for childhood asthma. Might this very high atopic predisposition have influenced or biased the overall results? From the present study, there is no data to investigate this question and the numbers were small. However, there were no obvious signs that the four mothers with no previous personal or family experience with asthma differed substantially from the other participants. Three had been identified as having progressed incrementally to regulation (Participants S5, S16, S17), and one instantly (S13).

What may have been more important in this study was the behaviour of mothers who had encountered asthma in a previous child. For them, the journey to regulation could have been influenced by their previous experience. Four mothers had an older child in whom asthma had been diagnosed (participants S2, S3, S7, S10). However, it has been noted that participant S10, in particular, who had an older daughter with asthma, and had experienced 'instant' change, appeared to have gained no benefit from her previous experience. In her interview, she talked very much as if encountering asthma for the first time. Within the whole group, no obvious differences were apparent and therefore it is unclear whether the range of the mothers' personal or extended family history had exerted any clear influence on their health behaviours in the index child. Nevertheless it might be informative for future studies to focus upon the first presentation in a first child.

Methodological limitations

In addition to the limitations surrounding the sample, two methodological points warrant highlighting; a) the authenticity of the data provided by the mothers, and b) the lack of data verification from the general practitioner.

Retrospective recall

The interview data in this study were based on the mothers' retrospective recall. It is known from studies of asthma self-management behaviours that recall can be unreliable[28;59]. Two measures helped to counter this potential drawback.

Firstly, the mothers were asked only to recall a relatively short span in their child's life. Similar studies have asked parents to recall over a much longer time frame. For example, Ostergaard studied parents of children aged 2-15 years[185]. In that study, the parents reported that asthma had commenced in the first year of life, meaning that, for some, they were recalling events from over ten years in the past.

Secondly, in this study the mothers completed a 'Lie' scale as part of the personality questionnaire, giving at least some indication of the likely authenticity of their responses[207]. The Lie scale assesses the tendency present in many people to present themselves as socially acceptable or to "fake good" when answering questionnaires about personal behaviour and beliefs. The mothers' mean lie score was 4.5 (Median 5, Range 0-8, SD 1.9). The maximum score for the lie scale is twelve, indicating that in general the mothers had rather modest scores which may suggest that their responses can be taken at face value.

No general practice representation

In this study, there were no comparative data available from general practice records to authenticate the mothers' reports, particularly in relation to the repeated visits for recurrent illness episodes occurring in the children. In Ostergaard's study, a small group of general practitioners were also interviewed[185]. Whilst located in the same geographical area, they were not the general practitioners for the family under study and therefore they provided a general indication of current management trends in clinical practice trends. Problems would have been encountered in Glasgow had this line of research been pursued, given how general practice care is organised, with relatively few single-handed practices and with no guarantee that a single or particular general practitioner for each child could be identified. Additionally, this would not have accounted for all consultations as it is known from the interview that at least some

of consultations occurred out of normal practice working hours and were made to local out-of-hours emergency service sites.

Alternatively, general practice records could have been checked for confirmation of the accounts of repeated visits. Instead, other measures were employed when sampling which counter at least some doubt. For example, case notes of children attending the clinic were examined by the researcher to identify children with a presenting history of recurrent illness episodes as recorded in a general practitioner referral, or in the asthma history as recorded by the respiratory consultant at the first visit to the respiratory clinic.

Despite such problems, the results of the current study accord well with reports investigating diagnostic delay around asthma in the young confirming that what was seen really does exist in practice[54].

Implications for clinical practice

The findings of this study should be of interest to many groups, particularly those engaged in planning and delivery of asthma care for young children with asthma. Some implications for clinical practice are highlighted here.

Improved diagnosis

Doctor uncertainty around the importance of the recurring asthma like symptoms directly affected the care and treatment the children in the study received. Diagnostic emphasis continued to focus on respiratory infections.

There is clearly a need for improved diagnosis of asthma in young children. As a basic minimum the use of a risk scoring system as has been proposed by Castro-Rodriguez[237] which includes for example asking about family history, and incidence of atopy in child and parents, could help diagnose some children presenting with recurrent wheezy illness episodes in general practice as asthma earlier.

Regular review and support

The study showed that the mothers underwent a process of behavioural development. Their progress was most difficult at the start. This suggests that when they are early in their asthma journey they might benefit from frequent review by a clinician or nurse with experience of asthma as opposed to the more common 3-6 monthly reviews that many clinics adopt. Whilst seeing such children more regularly would have resource implications, regular planned review is likely to be less costly than acute care provided at an out-of-hours service or during hospital admission. This would of course require that a prompt diagnosis had been provided, and the interaction between the health professional and the parent was focused on particular areas of need at that time.

Measures of assessment

It would also be helpful if there were simple measures available that could chart the progress the mothers were making in their self-regulatory journey. This study showed that the Zimmerman scale, the only currently available scale for assessing progress, has flaws. The present study provided some hope that simple alternatives could be developed. In particular, the Illness Perception Questionnaire for Carers stands out as being promising. It could be easily adopted for use in clinical practice, taking no more than ten minutes to complete and a further ten to code. In this study it was not used as a before and after measure, however, it might well document a mother's self-regulation progress and help clarify to what extent the mother felt in control of the child's asthma, particularly around use of medication.

Additionally, some simple questions might help the doctor or nurse to gain insight into the mother's experience. The opening question on the qualitative interview guide worked well in uncovering issues of importance to the mothers. Simply asking the question – "*When did you first learn that [child's name] had asthma?*" is likely to provide a useful starting point for a consultation. It allows the story to be told from the mothers' perspective, and it quickly highlights areas of importance to her.

The use of asthma action plans

Asthma action plans have been highly recommended in asthma guidelines and have been associated with improved health outcomes when used as part of a structured asthma approach[21]. A wide range of plans are available, and guidance on the most effective type was recently published[244]. Based on results from this study some additional 'good criteria' could be added. As noted, the mothers emerged as skilled observers, particularly in identifying their own child's early signs (prodromal signs). This is important as early intervention in an asthma episode, as witnessed by the mothers, can avert an asthma exacerbation. In children, it is known that symptom driven plans are effective[21;61]. Therefore by using asthma plans that focus on parental recognition of early warning signs and symptoms (observation in the self-regulation model) and providing guidance on what strategy to commence (enhancing judgement) mothers could be helped and encouraged to adopt a regulatory approach to their asthma care. This mimics Clark's study where general practice paediatricians were taught to adopt a self-regulatory approach to their asthma care behaviour with very good effect[57]. Indeed at the Royal Hospital for Sick Children in Glasgow, such an approach underpins asthma management and the asthma plans currently in use.

Future Research

Some potential issues and areas for future study have been discussed in the context of the Limitations. When distilled and re-grouped they offer a potential guide to sample selection when designing further study of the development of self-regulation.

In the light of this study, it is suggested that future study of self-regulatory development should include:

- Recruitment of a community based sample, who have never received hospital specialist asthma care or review, in order that the community development of asthma could be studied.
- A group of younger mothers closer to the national average birth-age of 29 years.
- First child only or families who have no family history of asthma or associated atopic illness in parent or siblings. Ensuring that the mother, or

carer under study, had no previous experience at confronting and coming to terms with asthma.

- Asthma presenting in a school age child, thus avoiding diagnostic uncertainty seen in the pre school age group.
- Lone mothers with limited social support.

One remaining point needs to be made. As noted in the Introduction the original concept behind the study was to develop an intervention designed to enhance self-regulation in parents of young children with asthma. In that sense the original aim still exists. In fact it has become even more relevant. Following the period of doctorate study the researcher has retaken up post as Clinical Nurse Specialist for Paediatric Asthma and again is working with families without a proven effective package of care to offer.

It seems clear that further study, involving an intervention, will be planned. It is likely that a successful intervention will target the following:

1. Child/asthma monitoring skills (observation)
2. Successful asthma intervention strategies (judgement)
3. Methods to assess response to the strategies (reaction)
4. Methods to enhance specific self-efficacy of the above

Final word

On a personal level my hope is that the findings of this study will increase clinical awareness of the difficulties facing mothers of young children with asthma when confronted by emergent asthma and that services will be designed to tackle their needs.

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TABLES

Table 1. Comparison between Short Stay Ward and Out Patient groups of self-regulation phase and self-efficacy scores

	Group 1 Short Stay Ward N=21	**Group 2** Out-patient N=27	
Self Regulation	Number (%)	Number (%)	
Phases 1 & 2	12 (60)	11 (42.3)	
Phase 3	7 (35)	9 (34.7)	
Phase 4	1 (5)	6 (23)	
Missing interviews	1	1	
Difference between groups			P= 0.16*
Self-efficacy	Median (Range)	Median (Range)	P Value**
Parental belief in treatment efficacy	16 (11-25)	21 (15-25)	0.005
Parental barriers to asthma management	13.5 (10-20)	13 (9-21)	0.178
Self-efficacy around attack prevention and efficacy	49 (32-61)	54.5 (13-64)	0.123

*Chi-Square
**Mann-Whitney U Test

Table 2: Individual characteristics of sample at time of interview

Subject	Age Mum (Yrs)	Age Child (Yrs)	Duration Asthma (Yrs)	Deprivation Category[2]	Marital Status	History of Asthma (✓), Eczema (E) or Hayfever (H)		
						Mother	Father	Other children
S1	33.2	4.7	3.8	3	Married	✓	Nil	Nil
S2	32.2	2.0	1.5	6	Married	Nil	Nil	✓
S3	40.0	4.4	3.4	2	Married	Nil	✓	✓
S4	41.1	3.9	3.4	1	Married	✓	E, H	Nil
S5	40.2	4.6	1.6	4	Married	Nil	Nil	Nil
S6	39.1	3.4	2.4	1	Married	✓	Nil	Nil
S7	34.2	4.3	2.3	6	Married	Nil	Nil	✓
S8	32.2	1.8	0.4	7	Married	✓	Nil	Nil
S9	21.2	3.5	1.2	6	Single	✓	Nil	Nil
S10	38.3	3.2	0.6	4	Married	Nil	Nil	✓
S11	21.8	4.6	3.5	7	Single	E	Nil	Nil
S12	43	4.9	3.6	7	Married	✓	✓	Nil
S13	37.6	2.9	1.8	6	Cohabit	Nil	Nil	Nil
S14	30.9	3.6	0.5	2	Married	✓	Nil	Nil
S15	33.8	3.6	1.6	2	Married	Nil	H	Nil
S16	46.7	4.03	0.77	4	Married	Nil	Nil	Nil
S17	42.9	4.9	3.2	1	Married	Nil	Nil	Nil
S18	29.8	3.9	0.9	6	Married	Nil	✓	Nil
S19	35	1.1	0.3	2	Married	Nil	✓	Nil
S20	34	3.2	0.6	4	Married	Nil	H	Nil
S21	35.8	4.3	1.2	2	Cohabit	Nil	✓	Nil

[2]Carstairs Deprivation Category; 1 (most affluent) to 7 (most deprived)

Table 3: Socio-demographic details of the sample recorded at time of interview

	N	Median	Range
The Mothers	21		
Age (years)		35.4	21.2 – 46.7
Years of Education			
Mother	21	12	11-13
Father	19	12	10-13
Marital status			
Single	2		
Married	17		
Co-habiting	2		
Divorced/separated	0		
Mothers occupational details			
Professionals	4		
Housewife	14		
Non-manual employees			
Manual employees	0		
Unemployed	0		
Student	2		
Partner Occupational details			
Professionals	6		
Non-manual employees	7		
Manual employees	4		
Unemployed	2		
Family history of asthma			
Mother	7		
Child's Father	5		
The Children			
Age (years)		3.9	1.13 – 4.9
Age at formal doctor diagnosis (years) - based on Mothers' recall		1.6	0.5 – 3.2
Duration of asthma (years) - based on Mothers' recall		1.5	0.2 – 3.7

Table 4: Means/Medians/Range/SD's of Individual psychosocial measures recorded at time of Interview

Variable	Items per scale	N	Mean	Median	Range	SD's
Conscientiousness	12	21	33.1	33.5	26-40	4.86
Coping (COPE)						
Active Coping	4	21	13.0	13.0	8-16	2.20
Planning	4	21	12.8	13.0	6-16	2.86
Seeking instrumental social support	4	21	12.7	13.0	5-16	3.13
Seeking emotional social support	4	21	11.8	12.0	5-16	3.52
Suppression of competing activities	4	21	10.2	11.0	6-14	1.97
Turning to religion	4	21	7.1	6.0	4-15	3.65
Positive re-interpretation and growth	4	21	13.1	13.0	7-16	2.60
Restraint coping	4	21	9.2	8.0	5-14	2.65
Acceptance	4	21	12.6	13.0	8-16	2.29
Focus on venting of emotions	4	21	9.8	9.0	6-16	2.82
Denial	4	21	5.5	5.0	4-10	1.83
Mental disengagement	4	21	7.5	8.0	4-11	1.91
Behavioural disengagement	4	21	5.9	5.0	4-12	2.24
Alcohol/Drug use	4	21	4.7	4.0	4-11	1.71
Humour	4	21	8.5	8.0	4-16	3.26
Eysenck Personality Questionnaire						
Psychoticism	12	21	2.0	2.0	0-5	1.48
Extroversion	12	21	10.1	11	4-12	2.48
Neuroticism	12	21	5.9	5.0	1-11	3.28
Lie	12	21	4.5	5.0	0-8	1.99
Illness Perception Questionnaire						
Timeline	6	21	3.1	3.0	1.8-4.0	0.5
Consequences	6	21	3.2	3.3	1.8-4.3	0.69
Personal Control	6	21	3.8	4.0	2.3-4.8	0.14
Treatment control	5	21	3.9	4.2	3-5	0.51
Illness coherence	5	21	1.9	2.0	0.8-3.2	0.67
Timeline cyclical	4	21	3.6	4.0	2.7-4.7	0.56
Emotional representation	6	21	3.1	3.1	1.5-5.0	0.79

FIGURES

Figure 1: The Historical Development of Self-regulation Theory