Aspects of care associated with sub-optimal asthma management in children

Mr Christopher Barton[1], A. Prof. Michael Abramson[2], Dr Nabil Sulaiman[3], and A. Prof David Clarke[4]

[1] *PhD Candidate, Department of Epidemiology and Preventive Medicine, Monash Medical School, The Alfred Hospital*
[2] *A. Prof and Deputy Director, Department of Epidemiology and Preventive Medicine, Monash Medical School, The Alfred Hospital*
[3] *Senior Lecturer, Department of General Practice, The University of Melbourne*
[4] *A. Prof, Department of Psychological Medicine, Monash Medical Centre, Monash University*

Backgrounds

This study will be nested within a Randomised Controlled Trial that aims to improve asthma care delivered by General Practitioners to children with asthma. However, families typically manage asthma at home. There is little research on how education delivered to physicians translates to improved management of childhood asthma by parents in the home, if at all.

Similarly, there is little research available exploring how parents cope with caring for a chronically ill 'asthmatic' child. It might be expected that providing parents with a written action plan would make management decisions for parents easier and reduce uncertainty about how to relate medication dosage to their child's asthma symptoms subsequently reducing feelings of anxiety. However, there is no evidence that written action plans are used by parents, or if they are the best format to provide information about asthma management. Recently, a qualitative study in the UK found that parents and physicians alike were against the use of written action plans because they removed control (Jones, Pill and Adams, 2000).

Other studies have utilised qualitative methods to study issues of adherence to asthma regimens, meaning of asthma and coping with asthma. These important issues will all be revisited in this study and relationships between them and how they relate to practical asthma management investigated. However, the unique aspect of the present research design is that these issues can then be related to actual asthma outcomes for children in terms of symptom control, and for parents in terms of their experience of stress.

It is hoped that the findings of this study will identify the difficulties and challenges experienced by parents in understanding and implementing physician advice for asthma management given the families social, economic and cultural situation. This information may then be used to improve the quality of care families receive from their doctors for the treatment of childhood asthma. Furthermore, by identifying successful strategies used by families to cope with the management of a child's asthma, this information can subsequently be used by GPs and asthma educators to empower families to take control of asthma and the fears associated with caring for a child with asthma. This will inevitably lead to children with better asthma control and improved quality of life.

Rationale

Despite effective pharmacological treatments, asthma continues to be a substantial cause of mortality and morbidity in Australia. There is evidence of poor adherence to treatment guidelines by both GPs treating asthma and patients themselves. Long-term adherence to the medication regimen by patients is critical for control of symptoms. However, adherence to the treatment regimen is typically less than 50% (Bosley, Parry and Cochrane, 1994). Focussing on patient aspects of adherence, issues such as the patients attitude toward their asthma, priority of health in their life, health beliefs, prior experiences, complexity of lifestyle, understanding of asthma and self-efficacy are all important determinants of adherence (NAC, 1999). Psychological and social factors may also play a critical role in asthma outcomes. However, mechanisms

linking psychological status and social status to asthma morbidity and mortality remain largely undefined (Wright et al, 1998). Considerable stress can be experienced by both asthma sufferers and their care givers that is attributable to the daily practical demands of managing asthma. How individuals manage stress is determined in part by the threat posed by the stressor and the resources the person feels they have at their disposal to do something about the stress. When what is at stake is important and coping resources are judged to be less than adequate, psychological distress is experienced (Lazarus and Folkman, 1984). Studies exploring coping strategies used by asthma sufferers have shown an avoidance coping styles to be associated with poor asthma outcomes (Adams et al, 2000) and non-compliance (Adams et al, 1997). Other studies have found that asthma sufferers may experience more feelings of anxiety and depression than healthy populations, and asthma sufferers with higher levels of anxiety and depression tend to be more non-compliant and at increased risk for near fatal asthma attacks and death due to asthma (Harrison, 1998), however evidence for this is not consistent between studies. Similarly, social factors such as availability of and use of social networks may influence ability to cope with asthma and be associated with poor self-management behaviour (Wright et al, 1998).

It is one of the roles of GPs to instil in patients the necessary knowledge, attitudes and skills to effectively manage their asthma. Poor asthma knowledge and attitudes to asthma care may be related to inappropriate coping strategies, increased psychological distress and poor asthma management practices.

An intervention has been devised to improve GP knowledge of asthma 'Best Practice Guidelines' for ongoing management of asthma in children aged 2-14 years. The present study will be nested within this larger randomised controlled trial and will use a case-control design. The objectives of the study are firstly, to examine the relationship between psychosocial factors and asthma outcomes in children, and secondly to determine which aspects of professional care are important in establishing and maintaining optimal asthma management practices by parents.

A combined quantitative and qualitative research design will be employed. The aim of the quantitative component is to evaluate the role of stress and coping in the management of paediatric asthma. In addition, there are four further aims for the qualitative component of the study. The first aim is to determine how perceived quality of care relates to patient health behaviour and subsequent health outcomes. This will involve examining the doctor/patient relationship from the care takers perspective and the process of seeking care. A second aim will be to explore the resources used by families to manage and control their child's asthma, and the resources used to cope with the stress of providing this care. A third aim will be to determine why certain asthma management behaviours exist by examining lay health beliefs and the social, cultural, economic and historical context in which the behaviour takes place. The final aim will be to examine relationships between coping with asthma management and the use of and quality of social networks.

Methodology

This study will utilise a nested case-control design and take place at the conclusion of a large randomised controlled trial designed to evaluate the effectiveness of locally adapted guidelines for the management of paediatric asthma.

Cases will comprise parents whose child took part in the RCT and has either been admitted to hospital, attended a hospital emergency department for asthma, or made an unplanned visit to the GPs office for asthma within six months of the beginning of the RCT. Controls will be parents whose child took part in the RCT and has not required emergency care for an asthma exacerbation in the same period.

There are two components to this study. Initially, a sample of 60 cases and 60 controls will be invited to fill in reliable and validated questionnaires as part of a *quantitative analysis* to identify psychosocial variables that differ between cases and controls. Participants will be mailed three questionnaires to complete including the Coping Responses Inventory (Moos, 1993), the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) and the Revised Attitudes and Beliefs about Asthma Questionnaire

(under development). Further patient information will be obtained from data collected as part of the RCT and will include demographic information, socioeconomic status and asthma knowledge.
Parents will then be offered the opportunity to take part in a qualitative study to talk about challenges they face managing their child's asthma. In-depth interviews lasting approximately one hour, and of a semi-structured nature will be used to collect data. A theme list developed from a review of the literature will provide an initial starting point, however the interview will be guided by the issues important to the informant. A preliminary analysis of the first few interviews will be used to refine the theme list, so that any further points of interest will be bought to subsequent interviews.

Sampling procedure for in-depth interviews

A combination of random purposeful sampling, quota sampling and theoretical sampling (Patton, 1990) will be employed. Cases and controls will be randomly selected from participants completing the questionnaires. Individual participants will then be assessed by the investigator to determine whether they meet pre-determined selection criteria of interest to the study. If they do not meet the criteria for selection the reason(s) will be recorded and the next randomly selected participant will be assessed. Criteria for selection of participants in this component of the study will include: completion of the quantitative component, that the child suffers moderate or severe asthma, gender quota such that a greater number of parents whose child is male are interviewed than are parents whose child is female (ie. proportionally representative of the normal population of asthma sufferers), socioeconomic quota such that at least one family from each socio-economic group (especially low income groups) are represented, and participants are willing to be interviewed. A minimum quota of **20 participants who are cases and 20 who are controls will be interviewed.** Theoretical sampling will be used to determine the final number of participants in this component of the study, which will be controlled by the emerging theory.