HEALTH-RELATED QUALITY OF LIFE, AND PSYCHOSOCIAL ASPECTS, OF ASTHMA.

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December, 1998.

To my mother and my daughter.

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Dr. Robert Adams
August, 1999

Acknowledgements

The financial support of The University of Adelaide via The Reginald Walker Scholarship for Medical Research, and of the Queen Elizabeth Hospital Research Foundation and Thoracic Medicine Unit is gratefully appreciated.

The assistance of Kieren McCaul, Head of the Health Statistics Unit, Epidemiology Branch, South Australian Health Commission, in performing the regression analyses in Chapter 5 is gratefully acknowledged. The assistance of Malcolm Rosier, Survey Design and Analysis Services, with the analysis using item-response theory measurement is also gratefully acknowledged.

I would like to thank Debbie Bates and Esther Carle for data collection, Louise Caldwell for data entry, and Di Handley for secretarial assistance. I would also like to express my thanks to Pam Gluyas, Karen Boath, and Nadina Labiszewski, of the Thoracic Medicine Research Unit, for occasional assistance with research work.

I would like to thank Brian Smith and Don Campbell for advice and guidance, and to express my enormous gratitude to Professor Richard Ruffin for his ongoing wisdom and support at all times.

Finally, I would like to offer my humble gratitude and appreciation to my wife, Catherine Hill, for everything.

Chapter 1

Introduction

In recent times the rapid expansion in the knowledge of the pathology of asthma and the biology of the inflammatory effector cells has emphasised the pathophysiology and the pharmacological treatment of asthma (1,2). However, psychosocial factors have been a feature of the literature of asthma over many years. There have been episodic reports in the early literature suggesting a psychological causation in asthma (3,4), and some reported psychological factors as the most important stimuli in asthma attacks (5).

The view of psychosocial factors in the asthma literature has changed over the past decade. Earlier articles (6,7) comprising reviews of fatal asthma and asthma made sparse mention of psychosocial factors. Inadequate education of the patient, poor compliance and a lack of access to adequate health care services have been cited as relevant to asthma mortality and morbidity. (6,7) Recent reviews have considered psychosocial factors relevant in defining severity and as possible precipitating factors in attacks. (8) Similarly, asthma management guidelines have recently included some discussion on psychosocial factors. (9,10). This has usually been in the nature of a paragraph on emotions such as anxiety and stress under factors that induce or aggravate asthma (11). It could be argued that there are already many studies of the way that patients see their illnesses. However, for a very common condition, relatively few have been concerned with asthma, and fewer have provided an account of how medical and non-medical inputs combine to influence attitudes towards disease. (12) Few studies have examined the relationship between clinical activity, temperamental, psychological and socio-demographic factors, and asthma health outcomes, particularly quality of life. The relationship between factors such as coping styles, self-efficacy, attitudes towards medications, adherence, socio-economic disadvantage, autonomy preferences, physician behaviour, organisation of care, patient satisfaction, quality of life and morbidity and

health service use, remains undefined. The use of quality of life measures in asthma in settings other than clinical drug trials has received insufficient attention.

Overview

One approach to examining the influence of psycho-social factors on asthma is to intensively study patients recruited from hospital clinics, and follow them prospectively to see what happens in terms of health service use, and quality of life change but also determine what is of importance to them. This is the approach that has been used in the work that forms the basis of this thesis. It has also been possible to compare outcomes between two different hospital settings with differing levels of specialist expertise available for care provision, in a non-randomised observational study.

This thesis presents original work conducted by the author during the Western Region Asthma Pilot Project (WRAPP). The WRAPP project was originally designed as a controlled intervention study of the effect of protocol-driven consultations based on current international asthma clinical guidelines for use in all hospital encounters for asthma patients. Purpose-designed software (MCARE Asthma, Medical Communications Associates, Belair, South Australia) was developed for entry and retrieval of clinical data at point of care, and to provide access to test results, graphical display of data and clinical decision support according to current management guidelines. Frequent and prolonged delays at implementing the system, due largely tonetworking and system compatibility issues, has meant that at the time of writing the system was not yet fully operational.

Consequently, a longitudinal, observational study of hospital asthma patients, recruited from two different settings, has been conducted. The Queen Elizabeth Hospital (TQEH) is a 400-bed teaching hospital of the University of Adelaide, located at Woodville, a suburb in north-western Adelaide. It has a fully operational and specialist staffed Respiratory Medicine Unit. The Lyell McEwin Health Service is a 200-bed hospital located in Elizabeth, 25

kilometres north of central Adelaide, with recent linkages to TQEH across the Divisions of Medicine, Surgery and Critical Care. Care is provided via General Medical Units with one session per week from a visiting Respiratory Specialist.

The data collected covers the four broad areas of asthma outcomes recently identified by the UK Clearing House on Health Outcomes (clinical events; psychosocial impact; self-management; patient feedback).(32) The longitudinal design with at least 12 months follow-up allows insight into the socio-demographic, socio-economic and psycho-social characteristics that influence asthma health outcomes.

Chapter 2 is a critical review of the literature on psychosocial factors in asthma, and of measurements of health-related quality of life (HRQL) in people with asthma. In the light of this review, the intent of this thesis is given in further detail.

Chapter 3 presents the methods, including the survey instruments used in the study to measure clinical morbidity and health service use, quality of life, and a number of psychosocial factors of interest in asthma research. The socio-demographic characteristics and clinical and asthma management features of the study population are described here. The surveys contained previously reported items concerning morbidity, including symptoms and activity impairment, (13) medication usage, (14) socio-demographics and socio-economic status, health-related quality of life,(15,16) coping styles of avoidance/withdrawal, active, (17) and denial, (18) self-reported general treatment adherence, (17) medication dislikes, (19) attitudes and knowledge of medication, management decision autonomy preferences, (20) satisfaction with illness, (21) health as a value, (22) socially desirable response set, (23) self-efficacy, (24) social support, (25) Physician Participatory Decision Making, (26) and patient satisfaction with care (27).

Chapter 4 establishes and compares the cross-sectional, discriminative, and longitudinal responsiveness validity of the Short-Form 36 Health Survey (SF-36) and a modified version of the University of Sydney or Marks Asthma Quality of Life Questionnaire (MAQLQ-M). The modification made to the Marks instrument was to alter the response options from a 5-point Likert to a 7-point Likert scale. This was done in an attempt to increase the reliability and responsiveness to change, making this scale potentially more useful as a clinical measure. Comparison between these two instruments was made to assess which demonstrated greater construct validity in asthma. Comparison of the performance of the SF-36 in a representative population sample with that in the WRAPP study sample was also made to assess whether it performed consistently across different administration settings. The MAQLQ-M and the SF-36 were both found to be highly valid and responsive instruments in assessment of asthma quality of life. The MAQLQ-M showed a stronger relation with clinical measures of severity than the SF-36. The MAQLQ-M was high levels of reliability and responsiveness, with minimal floor and ceiling effects, thereby demonstrating its usefulness as a clinical assessment tool.

Chapter 5 examines clinical and psychosocial factors associated with quality of life in asthma patients, and factors associated longitudinally with changes in quality of life over a 12 month period. Little work has examined the effect of temperament, coping, personality variables and socio-economic factors on the scores for validated quality of life instruments in asthma. If health-related quality of life is considered an outcome, then factors which may explain the variance in this outcome for people with asthma, such as self-management behaviour, self-efficacy and coping styles and socio-demographic factors, need to be elucidated in order for effective interventions to be designed. Avoidance and approach/active coping seems to affect behaviour and health outcomes for a number of chronic illnesses. Some work suggests coping may be of some relevance in asthma, but this pre-dates the current approach to management using regular preventive medication. If coping strategies influence self-management behaviours then we would expect an impact on

quality of life and health service use in a longitudinal study. The interaction between coping strategies and socio-economic factors, and their consequent impact on asthma behaviour and outcomes, has not yet been well defined. While provision of appropriate primary care may reduce the impact of low SES on asthma, other problems of severe economic disadvantage persist to impact on asthma outcomes. Whether these are primarily financial, such as costs of transport, home care, or medical costs, increased environmental exposures, psychological and behavioural factors, ethnicity, or other factors, is unknown.

The results showed a considerable effect of psychosocial factors on HRQL. Both baseline scores and changes over 3 months in HRQL were significantly related to coping styles, particularly avoidance coping, and to a lesser extent active coping. Economic disadvantage, as assessed by recent difficulties and concerns about costs delaying seeking needed care, rather than income levels were also significantly associated with HRQL.

Chapter 6 establishes and compares the minimally important clinical difference over time in scores on these two quality of life instruments. The issue of what change on a HRQL instrument is clinically meaningful to patients has not been well studied in people with asthma generally, and there are no published attempts for either the SF-36 or the AQLQ-M. Similarly, little information is available comparing the performance of disease-specific and generic HRQL tools in asthma in assessing a minimally important change, and whether one is superior in this regard.

The results demonstrated that the minimally important clinical difference for the MAQLQ-M was around 0.6, similar to that reported for other instruments using the 7-point Likert response scale. However this varied for different levels of baseline HRQL. The MAQLQ-M was more responsive than the SF-36 component summaries.

Chapter 7 examines the use of an alternative scoring methodology for HRQL tools, item-response theory methods, to score these two quality of life instruments and to compare this with traditional methods. The construction of HRQL instruments tends towards scales which focus on the mid-range of quality of life impairment, and are scored with traditional summative methods which may not produce interval levels of measurement. Using item-response theory to score the SF-36 and AQLQ-M it will be possible to examine if these scales are equally discriminating at all levels of quality of life, and whether similar changes in scores represent similar changes in actual quality of life at all levels of initial HRQL impairment. This would have important implications for interpretation of HRQL scores in research and clinical situations. This analysis showed the non-linearity of the Likert summative scoring model, particularly at the extremes of the HRQL range for both the MAQLQ-M and the SF-36.

Chapter 8 examines the factors associated with the self-management autonomy preferences of asthma patients. Few studies examining the effect of self-management in asthma have taken the "individual perspective as the point of departure for their analysis". (28) The patient is not looked upon as an individual making decisions about his or her welfare, and patient behaviour is viewed as inexpedient or a problem to the formal health-care sector. It has been argued that insights may be gained by viewing 'non-adherence' as a form of rational individual behaviour, given the circumstances of technology, prices, administrative regulation, and the individual's preference, knowledge and income (28). From this perspective, analysis of individual behaviour can help determine who would benefit from education programs and from targeted interventions to change the factors that determine behaviour. Determining what factors are associated with the preferences of individuals to participate in self-management decisions can assist with determining in which patients for whom guided self-management is appropriate, and those who are best suited to more directed approaches (29). The association between self-management autonomy and future health service use is also examined.

This analysis showed that individuals with asthma do not desire to be predominantly responsible for decisions regarding asthma management. what factors might be associated with the autonomy preferences. The factors associated with autonomy suggest a complex interplay between an individual's psychological make-up and personal experience both of life and of asthma, and the attitude and approach of the responsible clinicians. Higher autonomy was associated with less likelihood for future asthma hospital admissions.

Chapter 8 also examines the factors associated with the propensity of physician's to involve patients in management decisions, and the relationship of this to self-management autonomy preferences of asthma patients. Investigating what issues inhibit the development of stable therapeutic partnerships between patients and their professional carers warrants further research. Whether organisational factors, (eg the amount of time spent with the patient), can influence physician behaviour sufficiently that it affects how much patients are involved with their care is of some importance in an era of cost-minimisation. A greater propensity for physicians' to involve their patients in management decisions was associated with longer office visits and a longer tenure of the relationship between a specific physician and patient. A higher physician participatory decision-making style was associated with higher quality of life, and lower risk for hospitalisation.

Chapter 9 examines prospectively the factors associated with hospital admissions and repeat attendances at emergency departments for asthma. These are arguably the areas in which greatest gains could be made in terms of morbidity and health care costs. Evaluating the extent that psychosocial and socio-economic factors are risk factors for morbidity relative to clinical status will have implications for strategies to reduce morbidity. The results showed that predictably markers of asthma severity, along with socio-economic factors such as education and unemployment were associated with future health service events. In addition, avoidance coping and quality of care, as assessed by possession of a written asthma action plan were related

to future hospitalisations, and a dislike of using asthma medications was associated with re-hospitalisations.

Chapter 10 draws conclusions and implications from these results. Discussion of the possibilities for future research concludes this thesis.

Chapter 2

Psychosocial factors in asthma- Review of the literature.

Asthma management has increasingly taken into consideration the large body of emerging evidence on psychosocial factors which influence successful adaptation to illness. By considering these psychosocial determinants of health, medical care may be altered to improve patient outcomes whilst controlling health care costs. (1) Health status and quality of life are often better correlated with psychosocial factors than physical disease severity. (2-7) This issue is particularly complex in asthma where the disease severity is assessed indirectly and its manifestations are partly dependent on behaviour such as medication adherence and trigger avoidance by individuals. (8,9)

Promotion of Self-management

The importance of education of patients to improve self-care, and the introduction of various self-management plans have been given prominence in attempts to reduce asthma mortality and morbidity. (10,11) Management guidelines published from around the world have stressed the importance of self-management in asthma care. (10,11) The major elements of asthma management behaviours have been categorised into three areas by Krutzsch et al: attack prevention, attack management, and improvement of social skills related to asthma management. (12) Studies from Australia and overseas have suggested deficiencies in the skills necessary for self-management of asthma. These include delays in recognising and treating acute asthma attacks, medical non-adherence, lack of family support, low education, psychological problems, inadequate access to care and poor quality of care, and lack of continuity of medical care. (13,13,14,14-21) A number of a barriers to effective communication between doctors and patients have been identified, including rushed behaviour by doctors, inadequate information sharing by patients, inappropriate use of terminology by doctors and failure to use written instructions with inability of patients to remember what has been said. (22-25) There is evidence also that socioeconomic status and formal

education level may play a significant role in the effective promotion of self-management. (23,24,26,27)

Bauman reviewed 38 asthma education programs and reported improvements in self-management, compliance and psychological measures. The weighted mean effect sizes ranged from 0.49 for self-management behaviours to 0.62 for psychological measures. (28) Perceptions of success of asthma self-management programs in improving morbidity may outweigh the evidence of published results. (29) A meta-analysis of paediatric self-management programs found that they failed to reduce morbidity, with a pooled effect size on morbidity variables of 0.2. The authors pointed out that reliance on outcome measures such as school absenteeism or hospitalisations is arbitrary, as multiple factors affect these events in addition to asthma severity. They suggested that future studies should concentrate on evaluating skills and behaviours, as these are "more directly related to the teaching intervention, and less susceptible than morbidity outcomes to confounding factors that dilute the teaching intervention effect". (30)

A recent meta-analysis of adult programs indicated that asthma education alone without a self-management component, particularly a written asthma action plan, did not improve health outcomes. (31) A number of groups have now reported on trials of programs which contain a self-management component, with mixed success. The difficulty of defining what are important asthma health outcomes can be seen in this research. (32) Focusing largely on either health service use, symptoms or FEV_1 at single points in time, there have been inconsistencies between studies as to which outcomes are influenced by the interventions. (22,33-39) Illness behaviour and trigger avoidance seem less likely to be positively affected by these programs. (34,40) Inadequate medical treatment has hampered the effectiveness of at least one intervention. (35) The use of peak flow meters as part of action plan management has been effective in some studies. (41) However, no superiority over symptom-based plans has been demonstrated in controlled, comparison trials. (42,43)

It has been noted that complying with all aspects of the guidelines for self-management is a sometimes onerous task, and that the social consequences of frequent peak flow measurements may reduce their effectiveness in contributing to better asthma management, even in those with severe disease. (44) Others have found that patients are less likely to continue with treatment when it involves considerable interference with their daily activities. (45)

A recent review of studies in asthma self-management plans noted the variety of interventions used, making it difficult to determine which particular aspects contribute most to the results found. (46) The ability to generalise the results of these studies to the broad community of patients is also open to question. The drop out rates were so high in reports by Malo (40 out of 60 subjects), and Jones (49 out of 127), Yoon (20 from 76) and Ignacio-Garcia (26 from 94), as to suggest self-management may not be feasible for many patients with asthma. (33,36,41,47) Participation rates were low (30-50% of potentially eligible patients) in those studies that estimated the true target population. (29,36,48,49) Some studies also excluded or were unsuccessful in recruiting high-risk patients. These non participants may be those at greatest risk for adverse outcomes, such as smokers, persons with lower socio-economic status or with lower formal education levels, younger patients and patients with multiple previous admissions for asthma. (22,29,48-50) There is evidence to suggest that people who persist through programs are atypical of asthma sufferers in general. (51) It is also noteworthy that in the practice setting, sociodemographics can have a major influence on who is offered peak flow meters and self-management programs. (52) There is also evidence to suggest that attempting to teach self-management skills without addressing such issues as anxiety or financial and practical concerns will reduce the effectiveness of the intervention. (27,53)

The theoretical basis of interventions directed at enhancing self-management has received some attention. A number of authors have reviewed the application of psychosocial theories to health-related behaviour from the perspective of educational planning and design. (54,55) Green and Frankish

grouped categories of behavioural influence into three main factors: predisposing, enabling, and reinforcing. These major groupings contain the more specific influences such as knowledge, attitudes and social circumstances that determine behaviour. (55) Clark and others have stressed the importance of self-regulation, a concept derived from Bandura's social cognitive theory and the health belief model. (39,56,57) It involves three classes of influence on self-regulating behaviour: personal, behavioural and environmental. (56) A key organising concept of social cognitive theory is reciprocal determinism, in which environment, person, and behaviour are seen to be continually interacting. (58,59) It assumes that people self-regulate their health through the use of self-care strategies, setting personal goals, and monitoring feedback about the effectiveness of strategies in meeting their goals. (39) Applied to asthma this includes objective and subjective monitoring of asthma symptoms and medication taking, goal-setting and behavioural contracting to motivate change, and exercises to practice management methods and lifestyle modification. (60) These programs have stressed the importance of a partnership approach between carers and patients, educational activity that causes the patient to take clearly specified steps rather than merely provide information on broad principles, to recognise and respond to asthma signs and symptoms, reduce exposures to triggers, maintain appropriate medication regimes, normalise activities, and communicate with doctors and other professionals. (39) A large body of evidence in health promotion documents the crucial role played by persons having a sense of responsibility and control over health behaviours (55) It has been shown that knowledge about illnesses in general, and general attitudes to health problems have not proved very useful in predicting specific instances of health behaviour. (21,39,61-63) Self-efficacy, although increasing the likelihood someone will attempt a task, does not ensure behaviour will follow, although it may be a necessary prerequisite for a behaviour. (39,62-64) A critical dimension of the health belief model, the degree of belief in the possibility of having pathology in the absence of symptoms, is probably a critical variable in explaining self-management behavior in asthma. (65) It may take a belief, almost an "act of faith", to perform behaviors of chronic, maintenance asthma management. (65) There

are as yet few specific examples in the literature where self-regulation and its component processes are measured well in asthma. (66) One of the criticisms of health behaviour theory is that they do not appear to capture the non-linearities in life. (59) The dynamic interactions implied in such principles as reciprocal determinism are not well understood with regard to much health behavior. People are often faced with choices between alternative behaviors but theoretical constructs have most often been applied to doing a single behavior or not.

These theories share many common elements and themes. Stress and coping models, along with the theories of reasoned action and planned behavior, and the health belief model, share an emphasis on perceived control that can be broadly defined as self-efficacy. (22,65) The concept of "readiness" is a central component of intrapersonal theories of health behavior change. (65) Barriers are seen as inhibiting behavioral change. (65) Fishbein and others, in an effort to identify a small set of variables "believed to account for most of the variance in any given behavior" and cutting across specific theories, proposed eight key variables: intention, ability/skill, norms, environmental constraints, anticipated outcomes, self-standards, emotion, and self-efficacy. (67) Green and Frankish argue that there are stages of change, with a sequential hierarchy in factors that influence behaviour, and that predisposing issues such as beliefs, attitudes and motivation must be addressed before teaching skills or reinforcing behaviour. However, the constraints of time and resources often mean that several stages of change must be dealt with contemporaneously. (22) The transtheoretical model uses stages of change to integrate processes and principles of change from across major theories of intervention. (68) It conceives behavioural change as a process involving progress through a series of five stages using a number of definable processes. It assumes that there is no inherent motivation to progress through the stages of intentional change and that interventions must be matched to the individual's stage of change. In common with other theories and fitting the *trans*-theoretical nature of the model, most interventions using this model have focused on enhancing self-control. Little intervention work so far in asthma has had a specific stage-matched focus.

Evidence suggests that there is a threshold effect beyond which further effort in education delivers little additional benefit and that many other socioeconomic and psychological factors influence actual behaviour. (69,69,70) Continuing education of physicians about the management of medical problems has been demonstrated to improve clinical care and the compliance of their patients. (71) It has been noted that commonly in practice most education occurs in the doctor's office, independently of formal education processes. A means of effectively integrating education into the clinical encounter and continuing care of the patient may be more effective, and be more acceptable to a broader proportion of patients. (51)

In summary, self-management program interventions have had mixed success in improving patient outcomes. Difficulties in subject recruitment, high drop-out rates, and problems in defining exactly what are the key elements of the interventions have created doubts as to their precise role. Despite the extensive body of literature examining these issues, the relationship between patient education interventions, self-management behaviour, and asthma morbidity remains unclear. The interaction between various psychosocial, health care and economic factors, and asthma self care requires better understanding to produce more effective management interventions. In particular, the identification of sub-groups of the asthma population who would benefit from particular interventions is lacking. (70)

Psychosocial factors that influence health

Socio-economic status and health

Implied in the idea of self-management is an acknowledgment that the focus should not remain solely on individual psychology, but also consider the importance of the social dimensions involved, and of the social patterning of disability and handicap. (72) That is, health and illness have an inherently social character that is manifest in the social construction of our understanding of what it is to be well or ill. (73) Bury has conceptualised

chronic illness as a particular type of biographical disruption, where illness disturbs our expectation of how our life will proceed. (74) As such, this disruption highlights the relationship between coping strategies at the individual level and the varying and unequal distribution of resources available to individuals in society. As Bury notes, the social realities of disablement are such that unless such a perspective is adopted "many sufferers and their families will remain carrying untold burdens in silence, out of public view and uncared for by the community". (74) Chronic illness requires an adjustment strategy to be constructed and implemented and then continually developed for adaptation or acceptance to occur. Coping mechanisms "draw on knowledge, time, personal help or material effects such as aids or appliances". (72) The key feature here is long-term adoption or adjustment that must be made at an individual cognitive and emotional level, but occurs within the dynamics of daily lives and families and work environments. The complex nature of this interaction emphasises the importance of avoiding the simplicity of single direction of change thinking.(59)

The significant impact of socio-economic status (SES) on health in general is well recognised. The longitudinal Whitehall studies of British civil servants, and other studies have established that there is a social gradient: mortality rises with decreasing socio-economic status. (75-82) These gradients are observed both with educational and occupational status and are not explained by parents' social status or lack of an intact family during childhood. (75-80) Interestingly, they are also not accounted for by intelligence measured in school. As Marmot et al observe, this suggests that "indirect selection cannot account for inequalities in health". (76) Social deprivation and low education level have been shown to be closely related to function in rheumatoid arthritis at the outset and at five years, and that this is not related to compliance with treatment. (83)

Access to health care related to SES has been suggested as the major factor behind SES differences in health outcomes. (75) However, the differentials exist in systems of universal health care, in illnesses not amenable to treatment, and at the upper end of the SES hierarchy. (75,84) Vulnerability to

stress may be greater in lower SES groups, as the emotional impact of stressful life events is reputedly greater in people from lower SES groupings. (85) However, most examinations of differential vulnerability have focused on mental health outcomes; whether members of lower social status groups are physically more vulnerable to the effects of stress than higher status groups is unknown. (86) Health behaviours that impact on overall health also differ between SES groups. Increased smoking rates, decreased exercise, increased consumption of high fat diets, and lower health knowledge, are all associated with decreasing SES. (76,77,87-91) Ethnicity also influences health outcomes. Some data suggests this may occur at similar levels of SES, and that different minority or ethnic groups may have a different 'lived' experience of ostensibly the same SES level (as measured by income and education). (92)

In a review of the accumulating evidence, Marmot et al suggest that a combination of factors, including aspects of the work environment (low control, low variety, low satisfaction), social support, financial circumstances, and health behaviour (eg alcohol consumption) account for a large proportion of the social gradient in overall health status, and all of the gradient in depression and psychological well-being. (76) Wilkinson has further noted that there is a close relationship between relative inequalities of income, education and social class and differentials in mortality and morbidity. This gradient regularly found when comparing incomes within countries does not exist when comparing between countries of the OECD. The conclusion reached is that health outcomes in developed countries is not affected by absolute living standards as by relative living standards, with countries with less inequality having less mortality and morbidity. Thus, " the importance of relative standards implies that psychosocial pathways may be particularly influential". (93) Pincus and colleagues suggest that poor health in socioeconomically disadvantaged populations results more from unfavourable social conditions and ineffective self-management than from limitations in access to care. (94)

Critics writing from a sociological background offer two main sets of arguments why people with relative economic disadvantage suffer more ill health than others. One is a materialist explanation: choices are limited by economic and environmental circumstances. (95) Environmental and occupational hazards, combine with constrained incomes to increase risk exposure. The other set of explanations relates to cultural factors. Here, the reason for the lack of connection between knowing and doing lies in the power to choose, and the lack of control over their lives experienced by those with fewer material resources. (96) If choices about life are limited, then immediate comfort or ease outweighs long-term benefits. (97) The inconveniences of health behaviours are then not worth bothering about. At worst, health messages viewed as paternalistic or even authoritarian are actively resisted. (96) To ignore determining how and when such factors come into play with asthma management, is to court failure in improving asthma care.

The authors of the 1993 report *Goals and Targets for Australia's health in the Year 2000 and Beyond* identify the need to reduce health inequalities. They acknowledge that 'much of this social action will be outside the traditional boundaries of the health care system', and call for a 'broader framework for action' in pursuing better health. (98) The report places great store on healthy environments, setting quality targets for homes, workplaces, community infrastructure, schools as well as the natural environment. This challenges the reductionist nature of the biomedical model. (99) Some critics have also questioned the biopsychosocial model, with its continued emphasis on individual change, rather than change in policy to bring about fundamental, structural change in health care. (100) From this perspective, health is "inherently a social phenomenon embodying the quality of our relationships with one another". (100) Accumulating evidence of the critical impact of SES on health outcomes in asthma suggest these questions will need to be addressed before asthma morbidity is substantially improved.

Knowledge, behaviour and socioeconomic status

Kolbe et al in New Zealand found that major discrepancies existed between knowledge patients' had of what to do in an acute asthma attack, and their actual behaviour. (27) This was more marked in those with more severe asthma. The factors associated with the difference between knowledge and behaviour scores were similar to those reported to be associated with poor asthma outcomes in general. These were minority race, low income and education, and psychological morbidity of anxiety, pessimism, and feelings of stigmatisation. Appropriate behaviour in an attack was negatively associated with lack of knowledge, previous emotional counselling and business failure. However, the availability of an action plan was positively associated with timely and effective behaviour, suggesting that higher quality care may have an impact. (27) Those from more economically disadvantaged areas also recall having received any asthma education less often than the general population. A study from Melbourne found that asthma knowledge was associated with education level, exposure to previous material, not smoking, and referral to a private medical specialist, suggesting SES factors were of some importance. (101) Sibbald found that those with the highest morbidity from asthma delayed longest before taking appropriate action in hypothetical asthma attacks. Although one in four patients expressed strong feelings of stigma and pessimism about being an asthmatic, these attitudes were only weakly associated with hypothetical behaviour in this sample. (102) Rubin and Bauman showed that in children with moderate asthma, behaviour was related to knowledge and that those of higher socioeconomic status were more likely to adopt recommended practices. (69)

The difficulties in determining the relative importance to outcomes of environmental and psychosocial factors associated with socio-economic disadvantage, differential access to health care and intrinsic asthma severity has nor been overcome. (103) The lack of systematic and particularly prospective data has hampered our ability to fully evaluate this interrelationship. Garrett and colleagues have reviewed the evidence from New Zealand regarding factors associated with morbidity and mortality from

asthma. They concluded that financial barriers to continuous primary care in the context of relative economic decline contributed to poor outcomes. (15) Haas et al reported a highly significant correlation of both income and education with outcome following hospitalisation over three months. This appeared at least in part to be mediated by less continuous and less intensive medical management. (104) In one Canadian study, patients depending on an emergency department for asthma care were more likely to have lower income, live alone, have lived at their current address for less time, and were less likely to have an asthma action plan. There were no other indirect economic barriers to obtaining ambulatory care, such as lack of sick-leave benefits, identified in this group. (105)

The Australian National Health Strategy reports state that 'those with the lowest socioeconomic status have the highest standardised death rates in Australia'. For bronchitis/emphysema/asthma these rates for the lowest quintile were 98% higher for men and 39% higher for women. (106) Geographic analyses have revealed particularly high asthma hospitalisation and death rates in inner city neighbourhoods in the USA, which are characterised by high rates of poverty and higher proportions of minority group residents. (20,103,107) Similar findings elsewhere have suggested that sociodemographics and organisation of medical care have significant impact on morbidity, rates of hospital admission and emergency attendance. (15,16,18,108-110) Strachan and Anderson in the UK and Garrett and colleagues have observed that the variations in hospital admission rates were greatly affected by patterns of provision of health services and after-hours care, and associated socio-economic factors, more than major differences or changes in severity. (15,108,111) High rehospitalisation rates have been reported for ethnic minority or indigenous groups. (111,112) A recent study from New Zealand indicated that patients admitted to hospital with asthma have severe socio-economic disadvantage rather than lower quality of medical care. (16) Littlejohns and Macdonald analysed a UK study of disabled adults, including those who reported asthma as a contributing cause of their disability. Those in lower social classes were twice as likely to have severe asthma as those in the upper social classes. (113) A study from the

UK showed asthma mortality to be associated with social class and the proportion of households without a car. These authors also reported a tendency for mortality to rise with increasing distance from hospital, suggesting an effect of access to care. (114) Taytard et al found that those living in rural communities are less likely to contact a physician for asthma treatment than those living nearer to health facilities. (115) New Zealand evidence suggests those living near emergency departments use them more often than those living more distant. (109) Robertson et al found geographical isolation a factor in asthma mortality. (116) Data from Omnibus surveys in South Australia suggested that asthma morbidity was higher in country residents compared to city dwellers, despite similar levels of general practitioner visits and provision of asthma action plans. (26) Sociodemographics can have a major influence on who is offered peak flow meters and self-management programs, even within systems of universal healthcare, suggesting physician attitudes play some part in these interactions. (52)

There is some evidence that the diagnosis of asthma may be less used in some groups in the community. The diagnostic label of asthma historically may have been more utilised in higher socio-economic status groups. (113,117) Australian studies have shown lower recognition of asthma in children from lower SES areas than from neighbouring higher SES areas. (24) Ernst and colleagues demonstrated more frequent exercise-induced bronchospasm and more frequent symptoms in children from least advantaged homes. This was not accompanied with a higher level of doctor-diagnosed asthma. (118) However, a higher prevalence of asthma in lower income groups was found in a US survey based on doctor diagnosed asthma. (119) There is also some evidence asthma may previously have been underdiagnosed in elderly adults. In a geriatric population in Wales, over 40% showed significant acute responses to inhaled salbutamol but only 6% were being treated for asthma (120).

Nocon and Booth have shown the considerable impact asthma has on the social and personal lives of sufferers and their families. This extends into

many areas: employment, schooling, physical activities, social interactions, personal relationships and emotional well-being. They found that this social impact was correlated with disease severity. (121,122) Asthma creates dilemmas for those in the workplace. Concerns about loss of employment and stigma attached to asthma can lead to workers avoiding telling their employers of their condition, creating difficulties in getting sick leave or correct treatment. (123) Asthma related factors have been identified as "contributing factors to employment discrimination, job dismissal, and lack of career advancement". (123)

It appears that a constellation of factors associated with socio-economic disadvantage impact on asthma-related health outcomes. The means by which SES affects asthma remains unclear, with possible differences relating to management by individuals and availability of care, prevalence, environmental exposures, ethnic status, psychosocial dysfunction or other unspecified factors relating to low income as possible contributing factors.

Physician behaviour

Patient characteristics, such as age, gender, ethnicity or other attitudinal factors, may influence doctors' interpersonal behaviour with patients. This in turn could affect the extent to which patients are involved by their doctors in treatment decisions and planning. Kaplan et al studied what they describe as physicians' participatory decision-making (PDM) style as part of the Medical Outcomes Study. They assessed the tendency of physicians' to involve patients in decisions about treatment and the extent to which clinicians encouraged people to take responsibility for their own health. The factors associated with the least participatory visits with physicians were similar to those linked with poor asthma outcomes. These were lower education, minority status, discontinuity of medical care, being elderly or younger than age 30, a poor subjective rating of health, along with male gender. (124) Further work by these authors and others have shown that when doctors actively promote patients' this predicts statistically significant important transitions in health over time. (125-127) The authors did not report on other

psychological or personal coping styles of the subjects, nor did they survey patient attitudes towards enhanced autonomy in decision-making. Livert et al found that employment status had an important role in influencing treatment recommendations and on how physicians perceived patients with rheumatoid arthritis. They also found female physicians were more attuned to patients' psychosocial status and provided more information overall, although both male and female doctors provided more information to patients of the same gender. (128) Beisecker et al reported that medical trainees and primary care physicians felt that doctors should have greater input into medical decisions than should patients, regardless of the age of the patient. Female physicians and those with less medical experience and training advocated greater patient input into decisions, although this trend was not strong. (129) However, the impact on other aspects of care is less clear. Komaromy et al studied whether variation in hospitalisation rates can be attributed to differences in physician practice style. They surveyed the predisposition of physicians when making decisions about admission to be influenced by social characteristics that increase patients' vulnerability to illness, including homelessness and drug use. Although variation in hospitalisation rates did correlate with physician practice style, in a regression analyses this was not significant when adjusted for community sociodemographic factors. (130)

Research has demonstrated a relationship between doctors' providing education and advice, and their perception of the patients receptiveness and readiness to change. (71,131) Bauman et al have reported general practitioners are concerned that asthma self-management education may be 'dangerous', or might result in fewer consultations by these patients. They reported GP's seeing increased knowledge as the key to improved cooperation with treatment. (132) Whether this has changed over recent years with the initiatives of the National Asthma Campaign is unclear. The evidence is lacking as to the detrimental effects of self-care. In a review of medical self-care programs, focusing on self-initiated responses to symptoms in a variety of conditions, Kemper et al did not find any studies which reported any harm to the subjects because of inappropriate decision-making. (133)

It has also been noted that the time-consuming nature of patient education is a disincentive for doctors to be involved in many areas of preventive medicine. (134) Some years ago Williamson et al reported on a consistent set of tacit core beliefs held by physicians that inhibit doctor's from approaching the psychosocial aspects of their patients' conditions. These included beliefs about the physician's role being to concentrate on physical disease and a tendency to polarise problems as either biomedical or psychosocial, unexamined beliefs about patient wants, and fears regarding reacting to patients as people. (135) These beliefs can lead to a contest of definitions of illness between doctor and patient. Physicians may wish to emphasise the biomedical definition, while patients' want the definition to be in terms of their illness experience. (136)

Patients with asthma who report having a good relationship with their doctor are more likely to be compliant with therapy and with management strategies, and that this is largely independent of their level of knowledge about their illness. (137) The importance of this in relation to providing optimal asthma care is emphasised by a recent study by Ruffin et al from South Australia. They found that a major reason for patients obtaining their inhalers over the counter from pharmacies without a doctors visit was that they did not perceive any additional benefit from obtaining them from a doctor. (138) Kolbe et al also reported that the physician-patient relationship was positively associated with knowledge and behaviour in asthma attacks. (27) Eastwood and Sheldon in a recent systematic review of organisational aspects of asthma care found that patients managed by clinicians with a special interest and knowledge about asthma had better outcomes. (139) Yoon et al reported similar findings regarding attendance at education sessions. (36,48) Vollmer and colleagues have shown that patients cared for by specialist allergists conform more closely to management guidelines and report better quality of life, although they are likely to have more severe asthma. (140) Mayo et al felt that the motivation of the physician as well as the personality of the patients played a major role in the effectiveness of their self-management program. (33) Greenhalgh, in a review of shared care in diabetes, concludes that "care by disinterested and unsupported general practitioners is ineffective

and wasteful of resources". (141) Ben Sira showed that failure of the physician to give emotional support can hinder adequate coping with chronic diseases. (142) This interaction can have other effects. The Denver group showed that doctors sensitive to patients' increased level of anxiety with asthma prescribed higher doses and longer courses of corticosteroids to these patients. (143) A potential consequence of physician's increased interest in asthma may be an increase in prescribing costs for asthma medications (144), although one study showed a corresponding lower level of prescribing costs for other drugs such as antibiotics to compensate for this. (145)

Heszen-Klemens reported that two-thirds of physicians react with frustration and ego-defensive responses when faced with patient therapeutic non-adherence by patients. (146) There have also been marked discrepancies between patient views of difficulties with compliance and how physicians view these problems. (147) Others have noted a diversity of findings relating to exactly which behaviours on the part of providers lead to good rapport with patients and improve co-operation with management. (45,148) It appears that an effective relationship is a delicate balance between direction and evaluation presented in a manner acceptable to the patient. (45) These results suggest that there is a complex interaction between the attitudes and behaviours of doctors, and patient sociodemographic and personal characteristics, in determining attitudes to self-management and subsequent behaviour.

A more task-oriented approach by physicians may enhance patient self-management. Acquisition of skills is assisted by identifying personal goals, dividing tasks into very small, manageable units and then sequencing subtasks into a hierarchy of importance or difficulty. (149-151) Gonzalez et al, with particular reference to arthritis, contend that contracting for set goals and providing feedback are critical aspects of patient management that should consume a large proportion of effort in health education. (152,153) Thus, changing standard conduct in the clinic visit by the doctor maybe an early step towards enhancing self-management.

Specific psychosocial features

What can be learned from other illnesses?

It has been suggested that there is a core set of attitudes, beliefs and emotional states which predispose towards health. (1) While they differ in their specific formulations, these psychological characteristics are related to a broad range of health outcomes. They have been variously termed hardiness, coping strategies, optimism, self-efficacy, self-regulation, sense of coherence, sense of control, sense of connectedness, happiness, and pleasure. (1,56,154-159)

Increasing experience is being reported for a number of chronic illnesses. Accumulating evidence supports the contention that some personality dispositions and psychological states (e.g. fatalism, hostility, and emotional suppression) are linked to disease. (160) Risk of cardiovascular disease has been associated with depression, anxiety, and hostility. (161-163) A critical review of the impact of medication adherence on coronary heart disease outcomes noted that three large studies showed that adherence to placebo was associated with improved outcomes. The authors suggested that adherence confers a protective benefit on prognosis or may be a 'marker of some unidentified behaviour that is itself linked to prognosis'. (164) Prognosis in arthritis has been related to positive attitudes and how likely the person thought they would be to improve. (149) Studies in subjects with diabetes have also shown a link between psychosocial factors and glycaemic control. (165) Coping and appraisal of stress has been related to glycaemic control. (166,167) Reports also indicate that despite evidence of the benefits of intensive treatment and tight glucose control in preventing morbidity, psychological and social challenges make good glycaemic control very difficult to achieve in the practice setting. (165,168) Fawzy et al found that individuals who reported higher levels of emotional distress at the time of the diagnosis of malignant melanoma had lower rates of recurrence and death. Survivors also showed more active coping skills; those who used avoidance

coping tended to have more recurrence and lower survival rates. Distress may help motivate patients to mobilise coping resources and behaviours, and that acknowledging the reality of a problem is helpful in initiating adequate coping strategies. A brief cognitive-behavioural intervention reduced relapses. (169) Patel and Marmot have shown that those who use cognitive reappraisal as part of stress-management strategies in the management of hypertension, have greater reduction in blood pressure than those who do not. (170)

Holahan and Moos envision stressful life events and a reliance on avoidance coping appear to be risk factors that index a vulnerability to psychological or physical morbidity. Self-confidence, an easygoing disposition, and family support are viewed as stress-resistance factors. (160) Longitudinal studies of coping among patients with chronic illness have shown that regardless of diagnosis or illness controllability, patients who used emotional or passive strategies, such as wish-fulfilling fantasies or engaged in self-blame, tended to poorer adjustment to illness and lower functional status. (171,172) Problem-focused coping such as information-seeking had a positive effect. (171) Those who view the stressful transaction of an illness as a challenge have higher psychological well-being scores. (172) Both believing one can change the condition or that one must accept and get used to it, is related to greater approach or problem-focused coping. (173) Keefe et al have suggested that employing problem-focused coping may be less important in managing debilitating problems such as chronic pain, than not using negative coping strategies. (174) Ketelaars et al reported the coping strategies of 'avoidance' and 'emotional reaction' were significant predictors of HRQL in COPD patients, specifically .the 'well-being' and 'impact' scales of the St George Respiratory Questionnaire. (175) Buchi et al also found that those with the greatest tendency to use wishful thinking as a coping strategy (closely related to avoidance), had less improvement in a rehabilitation program for COPD patients. (176) Data from the Medical Outcomes Study indicated that avoidance coping was a very important predictor of poor adherence to medical therapies. (177) These findings suggest the presence of an emotion-focused coping group of wishful thinking, self blame, and

avoidance, which appears to be maladaptive when coping with chronic medical conditions.

The heterogeneous nature of the psychological problems experienced by persons with chronic illnesses is emphasised by one study which found thirteen unique patterns of depression in depressed persons being treated for chronic medical conditions. While patients manifest their affective distress in a variety of ways, self-esteem issues are significantly involved in almost half of the identified patterns (178)

Janz and Becker have shown that the most powerful of the health belief model's dimensions in predicting behaviour was 'perceived barriers' (or perceptions of negative aspects of a health behaviour). (179) Preventive health behaviours are often less accepted by those at greatest risk. In a recent study from Newcastle of cardiovascular disease, those who did not respond to invitations to be involved were more likely to be overweight or obese, or to have had raised triglycerides than those who did respond. (180) Mechanic has argued that "health actions that must depend on persistent conscious motivation" are unlikely to succeed in the long run. (96) Individual aspects of behaviour are integrated into a person's sense of self and of belonging to a particular social group. (181) Social isolation or lack of support for behaviour change from the person's social environment can be powerful factors working against change. As Byde has said, "individual behaviour change is extremely hard if it requires social isolation as well". (182) Numerous prospective studies have consistently shown increased risk of death in those with lower quantity and quality of supportive social relationships. (158,183) The effects of social support on reported health are complex, involving illness and coping behaviours. (184) There appears to be a threshold level of social support above which higher levels of social integration are not more advantageous. (158) Perception of emotional support, particularly an intimate relationship, appears to be the most powerful measure of social support. The number and structure of relationships may be less important than the perception of at least one confiding relationship. Henderson has pointed out that the social support received by an individual is

at least partly dependent on that person's behavior in maintaining social relationships. (183) However, the network structure is crucial for access to various kinds of functional assistance. (86) Others have contended that the evidence that social support has a predictive effect on health independent of personality variables. (158,185) The effect however has not been universally positive, suggesting that the particular situation of each individual will influence the buffering or moderating effect of social support. (184) Chronic stress may entail serious costs to the social network and thus erode perceived support over time, as distinct from acute situations when support may be mobilized. (86) The effectiveness of social support may be dependent on matching behaviours to what the recipient regards as supportive. (186) For example, close intimate ties may be best used for emotional support, but other relationships are better suited to the exchange of informational support. (187) In addition, people may benefit from different types of support during the different stages of coping with a stressor. (86) All of these issues make for difficult methodological problems in assessing the influence of social support on health, some of which, particularly the issue of sequences of stress and coping, have not yet been adequately resolved. (86)

In diabetes, patients who are involved in treatment decisions have better disease control and quality of life. (125) Evidence suggests that when doctors are less conversationally controlling and involve patients more in treatment decisions, patients have better outcomes and report higher satisfaction with care. (124,188) However, relatively little attention has been given to ascertaining patient's desires for participation in decision making. The few studies done in illnesses other than asthma have generally shown few patients preferred to have a major role in decision making. (189-191) Studies have reported greater decision making preference to be associated with younger age, female gender, higher education level, income, and occupation level, and a divorced or separated marital status. (192,193) However, most of the variance in patient responses was unexplained in these studies. Methodological concerns have been raised that may limit the interpretation of studies on patient preferences for autonomy in decision-making about treatment. (192) These include a lack of quantification of the

level of participation preferred, and the failure of the assessment of attitude to predict behaviour. Deber and colleagues have suggested that studies showing patients did not wish to be involved in decision-making failed to distinguish between two aspects of choice behaviour. They have shown that individuals are content to defer to physicians when the task involves identifying the options or the correct solution to a problem. However, people have a stronger desire to be involved in choosing and making trade-offs between outcomes. (194) A number of authors have found that regardless of how people feel about the level of control over decision-making, patients desire to be fully informed about their condition and treatment. (192,195) This does not necessarily translate into action. Miller et al reported findings that suggest that information seeking is used to reduce uncertainty but does not appear to be initiated in order to undertake controlling actions. (196) Braden also found no significant relationship between information seeking and self-help or problem-solving, enabling skills. (197)

The value placed on health by individuals has often been assumed by researchers to be high. However, in areas such as preventive health behaviour where health actions are undertaken in an asymptomatic state for the purpose of remaining healthy, the value placed on health may not be so high. (60,198) Unless health is valued highly there is no theoretical reason that believing one is able to control one's health will be associated with actual behaviour. (199) Lau and colleagues have indicated that any program designed to "change health beliefs will succeed in producing changes in health behaviours only among those who value health highly". (198)

Overall, the similarities between the psychosocial factors affecting asthma and those of other chronic diseases are striking. The issue of social support has perhaps received less attention in the asthma literature than elsewhere and may merit closer attention. Also, coping strategies have not been given the prominence in self-management education in asthma that they have in other conditions and this is an area that merits further examination.

Responsibility, interactions and coping

Becker et al have noted the importance to Western cultural ideals of the notion that individuals can control their environment and that taking responsibility for one's health is highly valued. (21) The risk is that the individual alone becomes responsible when things go wrong, and become vulnerable to being stigmatised and blamed for being the victim of severe asthma. This perception may be of some long-standing in individuals with asthma, even dating back to childhood asthma. (200)

The unpredictability of how an asthma episode will progress creates uncertainty and negative emotions, particularly if the patient has had previous severe episodes, and these impinge on the coping mechanisms adopted in acute asthma. Becker et al reported that 43% of the patients they studied wanted to manage their asthma unassisted and that this was related to a desire to remain 'normal', and the experience of being discounted or accused of non-compliance when presenting to the health system. (21) Nocon and Booth have reported people with asthma feel they are often greeted with disbelief and a lack of understanding by others. (121) Wakefield et al found that a feeling of annoyance at staff discounting the patient's assessment of their own condition was associated with repeat attendance at emergency departments for asthma. (201) Bosley and co-workers reported a third of their sample felt angry, ashamed or embarrassed about their asthma. (202) The patients' in Becker's study reported developing highly personalised and sometimes unorthodox markers of danger that would trigger them to seek help. These markers would not always accord with those that are specified in asthma management guidelines. The authors stress that the decision to seek help is a complex mix of fears, uncertainty, past experiences, and beliefs. (21) Patients with home nebulisers were reported by Campbell et al to present with more severe episodes of near fatal asthma (NFA). (18) Interestingly, Becker et al found that their patients used home nebulisers to avoid or postpone the loss of control to others in acute attacks and regarded this to be a positive benefit of them. (21) This highlights the sometimes conflicting goals of doctors and patients in asthma, and emphasises the importance of

seeking out patient preferences about management on the one hand, and recognising the presence of potential risk factors for delaying care on the other.

Coping has usually been viewed as a complex set of cognitive, psychic and emotional activities designed to moderate the impact of life events on physical, social and emotional functioning. The transactional model of coping construes stressful experiences as person-environment transactions, where the impact of an external stress is mediated by the person's appraisal of the stressor and of the resources at the person's disposal to cope with this stress. (203) Although a large body of literature has been produced over the last few decades on coping, and a wide variety of formulations developed to conceptualise it, two ideas appear central to the understanding of coping: one is variously termed approach, active, or problem-focused, the other avoidance or emotion-focused. (204-206) These are metaphors for cognitive or emotional activity that is oriented either toward or away from stress or threat. The effectiveness of these styles varies depending on the time frame and on the degree of potential control possible over the situation. Adaptation to stresses is mediated by cognitive appraisal of the stressful situation, which triggers emotional responses and choices of coping strategies. Research has suggested that when the individual views the situation as unlikely to be amenable to change, avoidance or emotion-focused coping predominates; when they are appraised as controllable by action, then more active problem-focused coping increases. (204,206) There are parallels between the coping strategies of various models and the change processes of the transtheoretical model of stages of change. (65) Change processes that involve substitution of alternatives for problem behaviours could be considered problem-focused coping strategies.

Although much research has proceeded on the assumption that problem-focused coping is more beneficial than emotion-focused coping, Thoits notes that there is no clear consensus in the literature on this issue. (86) Coyne and Downey have commented that across studies in many areas, coping strategies more often seem to have damaging effects than beneficial effects

on well-being. (207) It is likely that the effectiveness of any one strategy or style of coping may depend on qualities or properties of the stressor, e.g. chronic versus acute, controllable or uncontrollable. (86) There has been little recent work on the efficacy of coping on outcomes in chronic asthma during the period when advances in medication and understanding of pathophysiology have emphasised the chronic but controllable nature of asthma.

Level of education and income, seem to influence uses of different coping strategies. (205) Coping strategies may well be important mediators of the link between lower socio-economic groups and poor asthma outcomes. Maes and Schlosser found that cognitions and coping determined a large part of the variance in morbidity from asthma. Anxiety and coping with attacks in an emotional way was related to less well-being in general, and increased the likelihood of absence from work. Maintaining a restrictive lifestyle, akin to avoidance coping, and shame, also increased absence from work. (208)

Coping with asthma in everyday life can play an important role in determining the fear of acute breathlessness and also with the inconvenience or bother felt as a result of the disease. (44) This link suggests that coping behaviour can be seen not merely as a determinant, but as a constituent part of self-management of asthma. Behaviours that have a global impact on physical and mental health may also be considered a component of self-management. (60) Although research has tended to focus on situation-specific coping, the effects of these strategies may be depend on a person's dispositional coping style, which is a more enduring and generalised trait. Despite varying formulations in the literature, there are striking similarities in concepts such as 'sense of coherence' and 'hardiness' and 'dispositional optimism', which emphasise resistance resources and a sense of meaningfulness and self-confidence as being important in maintaining health. These styles tend to promote the use of active coping approaches, acceptance and information-seeking, and minimise avoidance coping, as adaptation mechanisms to stress. (203) Little work has examined longitudinally individuals' usual coping styles in asthma, and their influence on outcomes, particularly since the

concept of asthma control via self-management became the standard therapeutic goal.

Activity impairment is just one of several components of asthma experience. Different coping strategies used by individuals may produce different levels of emotional distress at similar amounts of activity impairment. Asthma self-management programs encourage a coping style that has been variously characterised as monitoring (196), problem-focused (206), or approach oriented (204). Hyland and co-authors have suggested that the goals of optimal physiological and psychological functioning are independent of each other, and argue further that it is possible that the coping styles encouraged by asthma self-education programs may lead to greater preoccupation with asthma, and hence increased psychological distress, despite a reduction in objective functional problems, such as activity restriction or decreased peak flow rates. They found that a self-management program did not reduce the "bother" from asthma, and that such a program may increase the bother associated with the cost and inconvenience of treatment, despite improved physiological control. The authors concluded that the "goals of self-management programs may be poorly related to the goal of reducing psychological distress", and that "psychological interventions may be able to change distress without necessarily improving lung function". (53) Focusing on asthma in daily life has been related to hospital admissions, possibly because this is a form of over-vigilant coping which can influence medical decisions. (208,209) However, because those who constantly "monitor" their health are more attentive to health threats, they may also adhere better to recommended health practices than those who blunt or avoid problems. (210) Hence there remains some inconsistency and complexity in the literature about the relationships between coping strategies and the efficacy of coping outcomes in managing the chronic physical and emotional aspects of asthma.

The fear and uncertainty about illnesses such as asthma, with its unpredictable acute episodes, can disrupt the application of problem-solving skills and contribute to the development of a 'learned helplessness response'. (197) Studies contributing to Mishel's uncertainty in illness theory have

demonstrated that length of illness experience is associated with lower levels of uncertainty. (211,212) Such findings suggest that counter to Seligman's proposition of generalised learned helplessness (155), patients do learn through continued experience with illness-related events despite continued exposure to uncertainties faced with chronic illness. The processes by which this may occur are not well determined. Some evidence exists that the influence of negative, disrupting factors on a targeted goal can be decreased by sufficient levels of enabling skills and the processes of self-regulation (problem-solving, self-belief, self-instruction). These learned self-help responses minimise the adverse effects of negative events on behaviour. (197,213,214) Crisis theory argues that dramatic events in a person's life engender a postcrisis period of psychological turbulence during which the individual is at heightened psychological risk. (86,160) Crisis resolution, which involves confronting stressful experiences and coping with them effectively, may increase resilience and lead to new social and personal resources. Positive thinking may help people profit from negative life events by allowing them to alter the meaning of events in positive ways.(160)

These formulations emphasise the idea of stages of change or illness experience relating to personal health behavior. (68) The experience of asthma has been characterised as a process or continuum which ranges from initial diagnosis to final acceptance of self-regulation. Snadden and Brown describe a transition that includes a need to integrate knowledge, experience and self-awareness before moving to acceptance and control. Changes involve a lengthy process with shifts in personal beliefs regarding the chronic nature of asthma and the importance of preventive measures and taking a proactive stance. (215) Progress along the continuum is accompanied by diminishing fear. This was mediated by a mentoring relationship of some type. The type of relationship was wide and covered a range from a single trusting relationship with a physician to a series of less intense relationships with several key people. The conception of differing stages of change with varying levels of fear and control in different patients may in part explain the conflicting results various authors have obtained with regard to the role such

factors as fear, panic, stigma and denial play in determining asthma morbidity. {313,315,48,316,319,321,322,234,762,759,251,320,318,324,462}

A number of studies have shown negative life events produce significant increases in emotional problems only when these events generate persistent or recurrent strains, as could typically occur with asthma. (86) Those using avoidance coping may not be accepting the chronic nature of their problems and may subsequently refuse to pursue illness management strategies or adhere to medication, because they irrationally seek a medical 'cure'. Authors have noted the value of acceptance of illness in developing active coping strategies in asthma care in children. (216) Qualitative research from Australia has shown patients can be characterised on a spectrum ranging from frustration and denial of their illness, along with negative perceptions of themselves and their doctors, to a position of acceptance and being partners in management. Those who have reached acceptance feel that they have moved along the continuum and have experienced a major life change. Their relationship with their doctor was a pivotal link in this process, and was the principal determinant of achieving a good outcome. Key features of this as described by these patients included the doctor establishing short-term personal goals with the patient and gaining commitment to undertake tasks to achieve these goals. (217) Inappropriately focusing on the negative aspects of disease, such as corticosteroid side-effects, have been described as risk factors for poor asthma outcomes. (218-220) Woller et al have shown that patients with a supportive relationship with a 'key' asthma figure are less likely to experience threatening aspects of steroid medication beyond justified worries about side-effects. (221,222) These results were echoed by MacDonald, who used qualitative methods to describe the meaning childhood asthma has for mothers of afflicted children. The overall theme that emerged was 'mastering uncertainty', with importance attached to actions taken by the internal self over a passage of time. (223)

This work would suggest that asthma self-management programs may need to focus not only on improving positive management strategies but also on reducing specific maladaptive coping behaviour. Patients' pre-set ideas of

effective coping may act as a barrier in some patients to building on their knowledge and skills. A study in children used the different phases of self-regulation by providing skills training based on the families' initial phase and was designed to advance them through subsequent phases. A family co-ordinator was a key part of the intervention by acting as mentor and change agent for the families. Emphasis was placed on encouraging patient's to seek information and ask questions regarding their management, and focus on self-beliefs concerning the condition. Physicians were asked to agree on set goals and plans with each patient and their families. The physicians were not informed as to the theoretical basis of the intervention, or otherwise formally trained in its aspects. Significant improvements were found on measures of asthma phase change, self-efficacy, mean peak flow rates, emergency room use, symptoms and activity days. (224)

Mood states

Asthma mortality studies have reported the presence of a number factors related to mortality, such as reduced compliance or adherence, reluctance or delay or failure to seek help, psychiatric caseness, and a range of psychosocial disturbances. (116,225-229) However, some have dissented from this view. Creer has asserted that the link between psychological factors and asthma death has been forced onto less than convincing evidence and that the notion that asthma deaths are all the fault of patients is a central myth of asthma. (230) Others have indicated that excessive use of beta-agonist medication, inadequate anti-inflammatory treatment, episodic or discontinuity of medical care, coupled with medical non-adherence, psychosocial dysfunction and age are important factors in excess hospitalisation and asthma death. (15-20,231) There is a consistency amongst studies on fatal and near-fatal asthma in that there are high levels of denial seen in these patients with a high index of psychiatric caseness. (227,232-235) Campbell et al have shown that those with high levels of denial were more likely to present with sudden collapse rather than earlier in an attack, suggesting that denial "may be a barrier to the uses of appropriate self-management strategies". (232) As used in these studies, denial is a concept developed by

Pilowsky and Spence in their work examining maladaptive responses to illnesses. It is described as a "tendency to deny life's stresses, and to attribute all problems to the effects of illness". (236) Findings of high scores in severe asthma patients in a number of reports from differing countries indicates it is potentially a key concept in understanding the psychological aspects of severe asthma. (232,235,237) The defensive strategy of refusing to accept the label of asthma, needs to be distinguished from phobic avoidance of feared situations or trigger factors. This is a separate but potentially significant problem. As Yellowlees and Kalucy discuss in their review of psychobiological aspects of asthma, this phobic, avoidant behaviour can be severely disabling and lead to a "vicious circle of fear, hyperventilation, panic and avoidance. (238) Others have noted how people with asthma assess their symptoms does not necessarily accord with seeking medical treatment. (115,239) Kendrick and colleagues have stressed that the "perception of the need for treatment must be distinguished from the perception of symptoms". (240) Other factors, relating to personal and social circumstances, affect the decision to seek treatment. (15,108,111) De Araujo et al found that patients with asthma who had greater psychosocial assets required lower doses of corticosteroids. They indicated that in patients' with asthma who had less psychosocial assets, those with less frequent life events fared better than those with high life event scores. (241)

Re-hospitalisation, which may reflect a combination of severity or multiple other factors including adherence and organisation of care, seems to be higher in patients with anxiety and pessimism. (242,243) Janson et al did not find any evidence that those in a population sample with diagnosed asthma had more anxiety or depression than those without asthma. (244) On the other hand, more recent work from Kolbe et al suggests that psychological morbidity may be underestimated in severe asthmatics, with up to 56% having significant anxiety and 19% depression. (245) Delays in initiating management have been associated with frequency of life events and previous emotional counselling. (245) Studies have indicated that in adult populations with asthma the prevalence of anxiety disorders and emotional disorders is higher than in controls. (246,247) Chetta and colleagues reported

significantly more psychological disturbance as measured by the Minnesota Multiphasic Personality Inventory (MMPI) in severe asthmatics than in those with less severe disease. (248) In the Medical Outcomes Study, asthma was the only condition other than depression that was associated with significant negative effects on Mental Health Component Summary scores of the SF-36 Health Survey, albeit on a small sample of 50 identified persons with asthma. (249)

Kinsman's Denver group published extensively on the contribution of psychological factors to asthma morbidity in the 1970's and early 1980's. (143,250-255) The concept of psycho-maintenance was developed to explain the increased morbidity of some patients. They noted there were large differences amongst people with asthma in their reactions and psychological adaptations to illness. (256) The implication drawn from this work was that individuals with certain psychological profiles were vulnerable to high asthma morbidity. (257) This literature drew attention to the distinction between panic-fear symptomatology, associated with the level of attention directed at breathing difficulties, and the quality of the patient's reactions in response to acknowledged breathing difficulties. (258) When high asthma-specific anxiety coexisted with high general anxiety, individuals tended to disregard symptoms, and medical outcome following intensive long term medical treatment was poor. In contrast, when high asthma-specific anxiety coexisted with average levels of general anxiety, people tended to be vigilant about symptoms, medical outcome was exceptionally good and hospitalisations were lower. The implication was that panic-fear served as a signal anxiety to improve asthma management, as distinct from general anxiety rendering the individual ineffective. (259,260) A Bayesian model for prediction of psychomaintenance was developed with good predictive ability in this group's hands for outcomes such as rehospitalisation. (243,261,262) This work has received little further development in the literature by other workers (263,264), possibly due to the sheer complexity of the measurement tools devised, including a battery of 719 questions. This group placed little emphasis on socio-demographic factors which may influence behaviour and morbidity. This research also predates the more recent concept of asthma being a

chronic, inflammatory condition requiring regular preventive medication (10), hence its direct applicability to the concept of guided self-management is unclear.

The relationship between panic anxiety and respiratory disease is complex. (265) In studies of patients following near-fatal asthma attacks, Yellowlees and colleagues found panic disorder to occur more commonly than expected. (266) It has been suggested that illness-specific panic symptoms may be mistaken for panic disorder, increasing reported rates of this condition in asthma. (240) Carr et al examined a group with asthma that reported a high level of spontaneous panic attacks, with 9.7% having panic disorder. In this group, a measure of catastrophic cognitions about bodily symptoms, but not pulmonary function, was significantly related to panic disorder. (267) These findings lend support to the idea that an elevated fear of bodily sensations ('anxiety sensitivity') may be important in the reactions of patients with asthma who panic. (268)

A recent longitudinal study suggested that mood states were influenced by asthma symptoms, but that the converse was not true. (269) Northrup and Weiner found that stress caused by asthma was related to rehospitalisation, which was unrelated to the occurrence of other stresses. (270) However, one study has found that nocturnal symptoms and the level of distress during asthma episodes were predictors for depression over a short-term follow-up of 2 months. (271) Hyland demonstrated that mood and evening peak flow values were correlated, suggesting that mood changes due to stressors during the day caused the falls in evening peak flow. (272) Relatives of adolescents with severe asthma have been reported to have higher rates of a number of psychological problems, including affective disorders and posttraumatic stress disorder, although not anxiety, than rates in epidemiological samples. Whether these disorders are genetically associated with asthma or represent an association with severe asthma because of environmental effects on the growing child is difficult to determine. (273)

It is possible that differing sampling frames can account for a large part of the discrepancies noted here. One difficulty with the research examining depression in such conditions as asthma is that survey instruments frequently include items that can be positively scored due to physical illness rather than mood change. (274) These include items on fatigue and sleep disturbance, both of which are common in asthma, particularly as severity increases. (32) The reporting of respiratory symptoms in general populations may be influenced by psychological status. (275) Nonetheless it would seem that at the more severe end of the spectrum of asthma morbidity, emotional disorders are common. It is not possible to determine whether the psychological problems were caused by or resulted from the severity of asthma, as most of the studies have been cross-sectional in design. Following a life-threatening attack, patients have been reported to respond by showing very high levels of denial or psychiatrically decompensating, with anxiety. (233) It is likely that a proportion of these patients who were intubated or had a respiratory arrest would have a post-traumatic stress disorder develop directly related to that experience.

Maes and Schlosser reported on an intervention which successfully reduced anxiety in asthmatics. Utilising Ellis' rational emotive therapy they sought to identify irrational beliefs which could be 'disputed' and changed. This process may influence the patient's perception of the disease and promote more effective coping strategies. The authors found that patients on the program were less preoccupied with their asthma and reported significantly less emotional distress, particularly anger and anxiety. There was also a reduced need for maintenance corticosteroid medication, a beneficial effect as the patients referred were considered over-users of medication. (276) Kinsman and colleagues have noted that interventions aimed at reducing anxiety have almost invariably been reported to be of benefit in individual case studies, but the results of more systematically controlled studies are clearly inconsistent. (277) They attribute this discrepancy to the variable effect of anxiety in asthma. They noted that asthma patients differ in their responses to stressors, and that "characterological anxiety" has different effects than anxiety focused directly on breathing difficulties in asthma. (277) This argues

against general, across-the-board application of anxiety reduction procedures in asthma.

Adherence

It is likely that adherence to therapeutic regimens is a critical mediator in the link between psychosocial factors and asthma outcomes. Adherence to inhaled therapies is low in patients with airways diseases. (255,278-280) Non-compliance with medications or with regular follow-up has been associated with worse outcomes in patients with severe asthma. (233,281-283) Most studies of outcomes in asthma have not made specific measurements of therapeutic adherence. Less is known about the factors, which may be associated with adherence to asthma management. Bosley et al found that depression, negative attitudes to doctor's advice and avoidance of self-care were associated with low compliance. (202) In their study, younger people and those with depression were more likely to drop out of the study. Kolbe and colleagues found adherence to be related to the rapport between patient and clinician. (27) Dekker and co-workers found compliance to be greater if the individual understood the prescription 'correctly', and had more symptoms or had previously seen a chest physician. (284) Osman et al described a high level of dislike of taking asthma medications among their sample, unrelated to the amount of dislike of the disability asthma may be causing in their lives. (285) Harding and Modell found a "deep seated distrust of long-term medication based on fears of possible side-effects and dependence". (286)

The effect of self-management programs on adherence is generally held to be positive. (287) In his review of asthma self-management programs, Bauman found improvements in compliance, with a mean effect size of 0.71. (28) These studies have relied on patient self-report to measure compliance. Van der Palen and colleagues used an electronic device to objectively evaluate adherence following a self-management program. They found baseline compliance levels were high compared to other studies. However,

they described low adherence to altering inhaled steroids in response to falls in peak flow measurements, even after an education program. (288)

Despite an extensive literature on adherence, there has been little consensus on the causes of poor compliance. (289-291) Much has also been written regarding factors which may be associated with improved compliance. (289,292-296) Many of the suggested solutions have focused on improving patient education, better patient/doctor communication, and on a variety of behavioural reinforcements. (287,294,295) Critics writing from a sociological perspective have noted that the perspective of the patient has often been ignored in much work on this topic, and have suggested that the research work on non-compliance is "covertly a literature about power and control", mostly revealing the "medical profession's worldview". (297,298) More recent work has sought to include the patient's perspective regarding adherence behaviour. (291,299) Hindi-Alexander and Thromm have written regarding asthma patient's "intelligent noncompliance", where regulating medication or even definite nonadherence may be learned and adaptive behaviour. (300)

An important theme in these studies is that the patient's decisions regarding medication can only be understood in terms of their beliefs, preferences and socio-cultural situations, and the meaning they attach to the disease itself. (297) Chronic illness can be conceptualised as 'biographically disruptive' to a person's expectations of life, calling for some sort of explanatory framework or 'narrative reconstruction' which will endow this threatening phenomenon with meaning. (72) Adams and colleagues, using qualitative methods, examined the meaning of asthma and medication for a group of patients in general practice. (297) These authors used sociological perspectives principally related to symbolic interactionism, labelling theory and identity. (73) These approaches emphasise that health and illness are perceived subjectively, and that people interpret and construct meaning in their lives largely through interaction with others. (301) Thus, social network linkages may help individuals' to reinterpret events or problems in a different light, depending on the importance to them of the role identity in which the events occur. (302) Adams et al found that their sample split into three groups,

which they characterised 'deniers/distancers', 'acceptors', and 'pragmatists'. Particularly important in how a person responded to the diagnosis was the degree of acceptance of the social identity of being an 'asthmatic'. Those who felt a high level of self-maintained stigma attached to having asthma, also felt threatened with a diminished self identity, and consequently denied or distanced themselves from the label 'asthmatic'. This perception was closely linked to the need for daily prescribed medication. Those who accepted the label of asthma had, following the diagnosis, re-interpreted what it meant to have asthma in a positive way. Central to this strategy was the importance these individuals placed on maintaining control via the use of regular preventive medication. This group had initially viewed the diagnosis negatively, but had undergone a process of moving toward acceptance similar to that described by Snadden & Brown and by Anderson in their patients. (215,217) The disability associated with a given impairment and the attitudes towards chronic illness and medication use are hence influenced by many factors such as the definition and perception of the illness, perceptions and feelings surrounding the self, the extent and quality of social support and other, as yet poorly recognised, variables. (72) Maes and Schlosser reported that shame contributed to hospital admissions and work absence. (208) Sibbald found feelings of stigma and low self-confidence to be associated with asthma morbidity. (303) Kaptein reported that length of hospitalisation was correlated with anxiety, feelings of stigma with being asthmatic, neuroticism, and hostility. Those at greater risk of rehospitalisation were less optimistic, more anxious and felt more stigmatised. (242) Feelings of stigma and pessimism about asthma, along with a panicky or fearful response to attacks, have been related to length of hospital stay, intensity of prescribed medication and frequency of hospital admissions. (143,250-255) Adams and colleagues contend that the success of the transformation process depends on reconciling the social identity of 'asthmatic' with the other social identities of the individual, to retain a positive sense of self. (297) Interestingly, neither 'acceptors' nor 'deniers' attended the practice's asthma clinic. One group because they denied they had asthma, and the other because self-control was a crucial part of their self-identity.

This evidence indicates that psychosocial factors play a critical role in medication usage by persons with asthma. It suggests that attempts to promote self-management or greater adherence to treatment regimens without actively engaging in a dialogue with patients and positioning asthma treatment in the life of the person is doomed to failure. Clearly, individual issues with therapeutic adherence will loom large in clinical practice. Easy telephone access to health professionals is one solution adopted by some workers in the field. However, in a review of medical self-care programs, focusing on self-initiated responses to symptoms in a variety of conditions, Kemper et al found that the use of telephone advice nurses tends to be underutilised by program participants.(133)

Autonomy

In recent years it has been suggested that it may be possible to improve health outcomes while reducing costs by helping patients to know when to seek professional advice and when to use self-care. (1) Once consumers are viewed as providers of care, then a core function of health care delivery becomes increasing self-care competence and autonomy. (1,133) An approach which matches physician practice style to patient informational and decision-making preferences has been advocated to facilitate this. (304) This involves the concept of the medical facility, which is a "measure of patients' wanting to know, coupled with their capability to know, about their medical problems". The physician style is matched to the characteristics of the patient, rather than adopting the same rigid approach to each individual, whether this approach be paternalism, complete patient autonomy or consumerism, or something in between. Within each doctor-patient relationship is a broad spectrum of negotiated power relations that defines patient autonomy and physician authority. (136) Holloway et al have reported on two studies in which the physician altered how he spoke with a patient based on whether the patient scored internally or externally on a measure of Health Locus of Control. They found a lack of an association between locus of control and predicted compliance. The authors suggested the concept of autonomy might be more suited to research in this area as it focuses on the

processes in the transaction between patient and physician rather than on expectations for control. (305)

The failure to alter therapy in a timely manner in asthma exacerbations has been reported in a number of studies. (17,18,228,232,306) Australian and international asthma management guidelines recommend each patient has a guided self-management action plan. (11) Utilising these plans requires the patient to be involved in decision-making and autonomous in initiating changes to treatment at the appropriate time. Although data about the extent to which people with asthma prefer autonomy in management decisions is scant, there is evidence to suggest that desire for information outweighs preferences for decision-making autonomy. Koning et al conducted an analysis of patients' opinions on respiratory care and found a very strong need for more information about diagnostic tests, prognosis and long-term use of medication. However, only one-third wanted more participation in decisions about their treatment. (307) Ellis and Friend found that 27% of patients who delayed altering their steroid medication in an acute attack did so because they desired to have medical guidance over their use at all times. (308)

Gibson et al adapted the Autonomy Preference Index (API) of Ende and colleagues (192) by making the content specific for asthma. Their subjects, including a group recently hospitalised for asthma, expressed strong desires for information but did not prefer to make decisions alone in asthma exacerbations. This preference became weaker as the severity of the attack increased, and was not associated with asthma quality of life. Younger patients sought greater autonomy than older people with asthma did. (195) Bradley and co-authors applied factor analysis to determine the relationships among patient's responses to a number of clinical scenarios. Asthma clustered with a group that included arthritis, hypertension, diabetes, and chest pain. It was also included in another group containing terminal cancer, abnormal mammogram, and health maintenance. The authors speculated that the scenarios in the former cluster contain illnesses easily recognisable or that would benefit from medical intervention. These conditions also imply

self administration of medications and long-term, complex therapy. The second cluster "may involve situations perceived by patients to be beyond control". This would suggest the possibility of the existence of at least two groups of persons with asthma who have markedly differing outlooks on their condition and the potential for effective intervention or control by self-management. (309)

These studies report patient attitudes rather than actual behaviours. The data suggests the issue of patient acceptability of self-management may not be as high as previously assumed. This may be one cause of the relative failure of asthma educational programs to substantially improve morbidity, despite improving knowledge. (30) Current evidence does not allow us to predict with any certainty which factors explain the varying levels of preferences for decision-making autonomy in different individuals. The extent to which a relative desire for physician guidance with decisions is related to inadequate teaching of skills and the approach of carers, with consequent effects on patient confidence and feelings of self-efficacy, is not easily established from the current state of research knowledge. In addition, the previous adverse experiences of those with more severe illness may make a further contribution to the lower desires for decision-making autonomy found in these groups in a number of studies. Methodological issues raised by Deber et al (194) concerning the conceptualising of decision-making autonomy into problem-solving and decision-making areas have not been examined with regard to asthma.

Summary of Psychosocial aspects of asthma

Although different investigating groups have used varying terms to describe psychological factors associated with poor outcomes in asthma, certain common features can be discerned. Individuals who tend to have low levels of confidence in their ability to cope with their illness, who tend to feel helpless and either excessively emphasise or strongly deny their distress, often have worse medical outcomes. Other features linked to morbidity are high levels of general anxiety, and either complete denial or an excessively

panicky response to symptoms. Refusal to acknowledge the chronic nature of asthma, or accept the implications of this with regard to medication regimens and other health behaviours, form a pattern of denial and frustration with asthma, and appear associated with persistently sub-optimal management. (217) This is linked with the failure to form a stable therapeutic partnership with a health professional. The often defensive, rather than task-oriented responses of physicians to these situations can compound the difficulties in establishing good ongoing relationships and effective management. The effect of these behaviours on asthma health outcomes has not been well elucidated.

One of the key issues in management of asthma will be deciding who will be responsible for initiating changes to the regime, particularly during acute attacks. The evidence regarding asthma patients' desires for autonomy in decision-making would indicate that these preferences need to be accommodated when planning management. (195,308) In particular, as attacks become more severe, there appears to be a desire to defer decisions regarding therapy to medical carers. (195) The degree to which this research is reflecting fixed personality characteristics and attitudes, compared to a lack of self-efficacy or confidence due to a variety of factors which may be amenable to intervention, is unclear. Which patients for whom guided self-management is appropriate, and those who are best suited to more directed approaches requires further research. (70) Methodological concerns surrounding this area of research need to be addressed. (194)

The coping strategies of avoidance and wishful-thinking has also been shown to be associated with poor outcomes in a number of chronic diseases. Important socio-demographic factors, such as education and income, seem to influence uses of different coping strategies. In asthma, these cultural factors are also associated with reduced self-management knowledge and less effective behaviour in acute attacks. The interaction between coping strategies and socio-economic factors, and their consequent impact on asthma behaviour and outcomes, has not yet been well defined. While provision of appropriate primary care may reduce the impact of low SES on

asthma, other problems of severe economic disadvantage persist to impact on asthma outcomes. Whether these are primarily financial, such as costs of transport, home care, or medical costs, increased environmental exposures, psychological and behavioural factors, ethnicity, or other factors, is unknown.

The response of the physician to reduced therapeutic compliance affects subsequent behaviour and outcomes in other diseases, and probably will do so in asthma as well. The potential for mismatched beliefs and expectations between those with socio-economic disadvantage, minority groups and health professionals may complicate this relationship. Investigating what issues prevent inhibit the development of stable therapeutic partnerships between patients and their professional carers warrants further research.

Bukstein has reported that the use of a point-of-care 'asthma report card' led to increased numbers of psychiatric referrals. He noted that in patients who had stable clinical disease markers but reported feeling their asthma was "really bad and my energy is down", physicians learnt to look for depression.(310) Kolbe and colleagues have shown strong associations between behaviour, outcomes and a positive response to a simple query regarding previous emotional counselling. (27) Determining if a limited number of items can be used to measure psychosocial distress as well as monitoring disease progress may contribute to better management if these can be integrated into routine care. (274)

The perspective of the patient and what is important to them has not been prominent in the asthma literature examining psycho-social influences on asthma patients. Little work has examined the effect of temperament, coping, personality variables and socio-economic factors on the scores for validated quality of life instruments.

Quality of Life

Increasingly, it is being recognised that the biological and clinical indicators traditionally used to evaluate health status and clinical interventions do not encompass the full experience of disease and treatment. (311) Clinicians often underestimate the functional disabilities of patients, particularly those related to social limitations. (312) For many chronic diseases, cure is not an achievable objective, and medical care is directed towards the alleviation of symptoms and disability, as well as mental distress. The outcome of a chronic disease such as asthma, which does not have the potential for cure with current medical knowledge, must relate to the well-being of patients. (313)

There are now numerous patient-completed questionnaires which address multiple areas of subjective experiences associated with illness, including quality of life, role performance and functional status. (314-317) Most measurement tools currently embody quality of life as defined by an individual's level of functioning, or as a person's perceived well-being. (318) Ware defined quality of life in terms of physical health, mental health, social function, role function and general health perceptions. (319) Spilker defines it as physical status and functional ability, psychosocial status and well being, social interactions and economic status. (320) Campbell describes 12 domains of life: community, education, family life, friendships, health, housing, marriage, nation, neighbourhood, self, standard of living, and work. (321) These definitions encompass a much wider understanding than the more limited one of functional status. As Ware has said, "It has become fashionable to talk about functional status and well-being as if they were synonymous with quality of life. Quality of life, however, is a much broader concept". (317) Gill and Feinstein have expressed this as "the belief that quality of life, rather than being a description of patient's health status, is a reflection of the way that patients perceive and react to their health status and to other, nonmedical aspects of their lives.....such as jobs, family, friends, and other life circumstances". (322) It is not clear to what extent the medical community should be held accountable for affecting these aspects of quality

of life. Gill and Feinstein argue it is crucial to include adequate measurement of individual patients' values and preferences in every study in order to assess the uniquely personal perception that is quality of life. This requires determining the opinions of patients specifically for each study and by "supplementing (or replacing) the instruments developed by experts". This definition presumes that quality of life is at least partly independent of health status. (318)

Guyatt and the McMaster group believe these criteria are too stringent, and they argued that it is reasonable to include elements of health status that people usually value (such as the ability to climb stairs), in addition to rating the subjective experience of living. They offered alternatives for researchers and clinicians assessing the literature. These include whether the measurements include aspects shown to be important to patients' lives in this or previous studies, or found to be valued by patients' in the clinical experience of the reader, and also whether individuals were able to directly express a value on their lives. (323,324)

Romney and Evans proposed a five component HRHRQL model with two components representing clinical features in a sick population (symptoms and signs) but aspects of health (physical and mental) in a well population. Three other components represent psychosocial functioning (friendships, well-being, employment) in both types of population. While in a chronically sick population (with cardiac disease) the predominant direction of influence is from illness to psychosocial functioning, in a healthy population psychosocial functioning appeared to be critically important in maintaining and promoting health. (325) The authors did not report if quality of life varied if subjects were stratified by disease severity. The differences between healthy and unwell populations raises the question of whether measures designed for one purpose (eg cross-sectional population studies), are valid for other purposes (eg longitudinal clinical studies). (315,323,326)

The concept of health-related quality of life implies that people can analyze quality of life into its health and non-health-related components. (327) The

subjective assessment of "well-being" opens up "quality of life" to a wide array of potential psychological and social influences that are known to affect personal judgements and evaluations. (328) Some authors have argued that the conventional, multifaceted approach to conceptualising quality of life, that of aggregating several indices, tends to reduce the information available from different domains, and fails to recognise that quality of life is inherently multidimensional. (315,329,330) Hyland has argued that this approach reduces the understanding of the causal sequences that operate on specific outcomes, not on what are conventional aggregations. (315) Thus, morbidity causes symptoms, which then cause problems in daily life. These problems cause evaluations by the individual, i.e. judgements about quality of life. This interdependence of quality of life, disease morbidity, and psychological factors such as mood states, coping and cognitive styles, and their causal interaction tends to be discounted in the conventional approach. (315) He further argues that quality of life scales do not measure functional ability, but the "willingness to complain about perceived functional disability" (331) Bauman has proposed that asthma outcomes be considered in terms of morbidity, or the negative consequences of having asthma. Quality of life here includes the "impact of physiological and functional morbidity on psychological status, social well-being and life-style. (66) It is in this social context that disability actually occurs, and psychological variables can have a major impact on how a disability evolves. (327) An alternative view has been articulated by Muldoon et al, who have argued that aggregating the different kinds of information obtained by asking about well-defined functioning on the one hand, and subjective health appraisal on the other, is illogical, and that domains should be kept separate. (318) In chronic diseases the literature would strongly suggest that psychological phenomena are critical dimensions in the measurement of outcomes and quality of life. (328) The psychological states that affect the evaluative or subjective appraisal of quality of life assessment are likely to be less amenable to short-term interventions than the problems or symptoms experienced by persons with a condition. (315) There is some evidence in asthma to support this reasoning. (332,333)

The commonplace observation that people with the same level of physiological disease function differently reflects the impact of non-health related factors. (66) If people make life choices that seriously restrict their environments, they minimise physiological morbidity but increase functional and positive quality of life morbidity. However, this avoidance style of coping, by reducing the incidence of negative life events, may improve quality of life as assessed by most measurement scales, as these focus on problems with doing activities. (334) Hyland has noted that the "gap between desire and attainment can be reduced just as much by diminution of desire as it can be by increased functional attainment". (331) In this sense, functional status is a relational concept, requiring an understanding of what is expected of a person by themselves and others. Conversely, a clinically effective drug therapy may lead to an increased level of activity which in turn increases the burden of symptoms. An understanding of how and to what extent morbidity is exchanged or compensated for may assist in understanding why interventions in asthma often appear not to have large effects. (66,314) These considerations also indicate a need to evaluate the effect of coping and cognitive style influences on quality of life scores, for example whether people achieve apparently good scores by trading off positive experience for avoided morbidity.

Generic versus disease-specific instruments

Broadly, quality of life instruments are either generic measures, evaluating general well being, or disease specific, with items tailored to the impact of specific diseases, such as asthma. The uses and relative benefits of either approach continues to be debated. (314) Advantages claimed for generic measures include their applicability to the general population, to patients with multiple conditions, and that the use of common methodology allows research comparisons across different diseases. (335,336) They have generally been thoroughly tested and validated in a variety of settings and populations. The breadth of issues covered may reveal important, but unexpected impacts of disease or treatment and establish an overall assessment of the patient's life. (337) These measures are less oriented to specific symptoms than disease

specific tools. These characteristics may make them less sensitive to the influence brought about by drugs, which often act principally on symptoms. (338)

Some evidence suggests that disease specific measures are more likely to be responsive to changes over time in asthma. (314,323,332,339-341) Whilst a number of different measures have shown changes in a variety of populations with asthma, these have not been consistently responsive to interventions. (342-348) Some authors have suggested this may in part be due to the characteristics of asthma, with asymptomatic periods of good control affecting the results of scales using short time frames for sampling. (314) Scales sampling from physical functioning domains have tended to be more sensitive to change that those dealing with emotional or mental health. (332,343,349)

A difficulty of disease specific measures is in making comparisons across populations, particularly between normal subjects and patients, and across diseases. Some asthma questionnaires emphasise this by creating personalised instruments, where the patient rates disabilities in specific areas of their choosing. (343) This approach has been likened to the clinical reasoning and process of patient care, (340,350) and may increase the responsiveness to change within subjects, for use as an outcome measure. (343) This has not been a universal finding however, with one recent study indicating a individualized measure performed less well in detecting change than a standardized instrument. (351) The use of different parameters in different patients also makes it difficult to define a population or to compare clinical trials and interventions with this type of tool.

Global self ratings of health are simple survey instruments, and longer measures usually include a global rating. Evidence exists to show that they are independent predictors of survival, particularly in the aged. (352-354) Even people with objective disease seem to do better when they believe themselves to be healthy than when they believe themselves to be ill. (354,355) The relationship of this simple measure, when controlled for other variables , to predict outcomes in asthma has not been reported.

Utility measures of quality of life are derived from economic and clinical decision theory, and concern how a rational decision maker should behave when outcomes are uncertain. (356) Utility here refers to individual preferences or value for those outcomes or health state. (314,323,332,340) This approach has the theoretically attractive advantage of being amenable to cost-utility analysis and can allow comparisons between different diseases. However, utility scales are difficult to validate and may not pinpoint the individual aspects of quality of life in which impairments are occurring. (357,358) Controversy exists about the definition of utility values and the scaling methods used, and the effect and context of the framing of health state descriptions on the results obtained. (357,359-361) They have been used only infrequently in asthma research. (341,357) Rutten van Molken in a comparative study of four HRQL instruments used two utility scales and both proved relatively insensitive to change, although a rating scale was superior to a standard gamble approach. (332) Large differences have been reported in the values assigned to health utilities by asthma subjects depending on the method used to measure utility. (362) Jones has suggested that these problems call into question the validity of cross-disease treatment comparisons and attempts to perform cost-utility comparisons across different diseases and settings. (341) Conflicting evidence regarding the clinical responsiveness of utility scales has been reported in other areas. (363) It is possible more recently developed multiattribute utility indices may overcome these concerns, but no longitudinal studies have been reported on their use in asthma. (364) One study has shown good cross-sectional correlations with the Asthma Quality of Life Questionnaire (AQLQ) developed by Juniper et al and the Health Utilities Index (HUI), a multiattribute utility scale. (365,366) Greater understanding of the psychological, cultural and medical influences on choice and decision making are needed before the methods are used more widely.

Generic Quality of life instruments used in asthma

The Short-Form-36 Health Survey (SF-36) is derived from the work of the Rand Corporation in California into measuring health status, particularly the Medical Outcomes Study (MOS). It was designed as a generic health indicator to be applicable to a wide range of types and severities of conditions. It consists of eight scales that measure both physical and mental concepts of health in several different ways. (317,367) These include measures of behavioural functioning, emotional states, social and role functioning, as well as perceived subjective well-being. Extensive validation has been done for the SF-36 on numerous populations around the world, including Australia. (329,368,369)

However some question can be raised about the generalisability of these results to populations with more severe asthma. Bousquet et al found in a French sample that the SF-36 scales were able to distinguish patients with different levels of asthma severity according to Aas symptom score {1300} and FEV_1 (336). Only 28 of the sample were of a clinical severity that justified an Aas score of 5, the level of disease requiring anti-inflammatory medication, and only a further 42 were in category 4 (336). Rydman and colleagues reported a significant correlation between peak expiratory flow rate and only one scale (Physical Functioning) of the SF-36 (370). Other reports show that patients with severe asthma as defined by dependence on oral prednisolone have mean SF-36 scores significantly lower than US population norms. (371,372) Another report in 102 patients with "chronic lung diseases", including asthma, found SF-36 scores differed significantly between disease severity, as measured by symptoms, for the domains of general health perception, physical functioning, physical role and vitality, but not in other domains. (373) However, one report found that scores for mild-moderate asthmatics did not appear to differ from the scores for the SF-36 US norms, suggesting that the SF-36 may not be adequate to capture important quality of life differences in mild-moderate asthmatic populations. (371) Conversely, van der Molen et al reported that in a sample of 110 persons with mostly mild asthma that the SF-36 showed excellent cross-sectional construct validity in

its ability to discriminate in asthma severity, comparable to disease-specific measures. (374)

One study has compared the responsiveness to change with interventions for the SF-36 and asthma-specific measures. (351) Ware and colleagues found the SF-36 valid in a population with mild to moderate asthma (95% rated their health as "good" or better). The physical scales and physical summary measure were most useful in discriminating between patients differing in severity of asthma, as well as treatment impact. In comparison with asthma-specific scales, the SF-36 scales were less valid in comparisons of patient groups formed according to changes in various clinical indicators, as well as in treatment comparisons. (351) Okomoto et al found that SF-36 scores improved in a cohort of asthmatic patients treated with fluticasone propionate in the dimensions related to physical activity and in general health perceptions. In addition, after one year of treatment, scores in one additional dimension, vitality, also improved significantly, suggesting that some improvements in health-related quality of life may require a longer period of time to improve or to become sufficiently evident to the patient. (372) However, in another study this group reported significant improvements in scores for general health perceptions, vitality and mental health scales after only 12 weeks of intervention treatment. (375) In a cohort treated with fluticasone, Noonan et al found improvements only in the physical function domains and in general health perceptions, despite significant improvements in symptoms, lung function, and oral prednisolone use. (376) Another generic scale, the Sickness Impact Profile (SIP), has been shown to be insensitive to clinically worthwhile improvements in health in asthma, compared with a disease-specific tool. (332,377)

The identification of areas of altered quality of life possibly not directly related to respiratory limitations maybe an area where general health measures have an advantage over disease-specific asthma quality of life questionnaires in directing management and further research. Given the conflicting evidence from clinical drug trials regarding the sensitivity to change in some domains, further work is needed to assess whether the SF-36 is an adequate measure

for intervention trials and in clinical practice, or whether it is best used in combination with disease-specific tools. (351)

Limitations with a number of the scales have been reported. The social functioning scale and both role limitations scales are very narrow and have weak scaling properties, leading to extreme floor and ceiling effects. (368,378) The high proportion of people in the general population who score on the ceiling of many scales, coupled with the large proportions from groups such as the frail elderly and those with complex medical problems scoring on the floor of some scales, suggests the SF-36 may be inadequate in describing health at the extremes of quality of life. (368,378,379)

The developers of the SF-36 have reported that a large proportion of the reliable variance in the eight scales of the survey is accounted for by two components derived from factor analysis comprising physical and mental dimensions of health. (249) These psychometrically-based summary measures have the potential to reduce the number of statistical comparisons needed to analyse the SF-36 without major loss of information. The summary measures have the theoretical advantages of reducing confidence intervals around individual scores thus making fluctuations in individual scores less likely to be due to chance, and thereby facilitating their use in monitoring individual patients in clinical practice. The summary scales are scored by norm-based methods which also eliminate floor and ceiling effects. (249) They reliably define many more levels of health than the eight scales, increasing the discriminative properties of the instrument. (249) To date little is known about the trade-offs between the advantages gained by reducing the number of statistical comparisons versus the loss of specific effects measured by a particular scale. Ware et al have argued this depends on the extent to which results are the same across conceptually related scales, or concentrated in an individual scale. (380) Ware and colleagues reported that the physical summary scale was responsive to change in subjects with mild asthma over the course of an 8-week clinical drug trial. However, it was less sensitive than an asthma-specific measure. (351) Given the reported limitations with a number of the scales in their discriminative ability for small

differences in function it is likely that for many purposes the summary scales will provide better information. However, Shadbolt and colleagues found only one dimension of health in a population of Australian hospital patients. (378) They suggested that different samples may produce one or two components, and that this may relate to the closer association between mental and physical health in people requiring hospitalisation compared to the general population. Socio-demographic variables have also been reported to influence scores on the SF-36, indicating the need to evaluate socio-cultural dimensions when measuring quality of life. (378,381) The responsiveness of the SF-36 scales and summary scales to longitudinal in a population with more severe asthma, and the factors that may influence this, have not yet been determined.

Asthma-specific Quality of life instruments

There is a growing body of evidence that conventional indices of asthma status such as FEV_1, symptoms, and hospitalisations are only weakly correlated with patient's perception of their functioning and health state. (358) A number of asthma specific quality of life measures have been developed in recent years for use in research and clinical settings. These include the Juniper Asthma Quality of Life Questionnaire (AQLQ), the Living with Asthma Questionnaire (LWAQ), the St. George's Respiratory Questionnaire (SGRQ), and the University of Sydney or Marks AQLQ (AQLQ-M). (339,343,346,382,383) Critics have contended that these type of measures should be more properly referred as disease-targeted instruments. Item selection is made so that they evaluate areas of life and functioning affected by asthma, but such things as breathlessness cannot be exclusively influenced by asthma only. (384)

There are two major schools of thought as to how items should be selected for inclusion in a disease-specific quality of life questionnaire. Juniper et al have described one approach as the 'impact' method. This technique asks patients to identify the items of impairment that are important to them in their everyday lives. Those items identified most frequently and rated most

important are selected for the final questionnaire. (343,385) This method is consistent with what Feinstein has called "clinical sensibility". (386) The more conventional method is to use psychometric techniques such as factor analysis, which selects items primarily according to their relationships to one another. This approach has been used by a number of groups in developing their asthma-specific questionnaires. (339,345,346,348,382) This method of factor analysis also can be used to establish statistically whether there are meaningful sub-scales or domains or not. If the intercorrelations within sub-scales are substantially more than the intercorrelations between domains then the scale can be identified, psychometrically, to have more than one dimension. (316,339)

Marks et al derived items for their questionnaire from focus group discussions with patients and from the clinical experience of nurse educators and the investigators themselves. Although participants were asked to consider only the social, emotional and cognitive implications of asthma, symptoms still loomed large as a chief concern of people with asthma. The authors note that the use of "principal components analysis and Cronbach's alpha to assess the items for the AQLQ means that the final questionnaire does not necessarily reflect all aspects of the impact of asthma but measures a homogeneous domain which we have labelled quality of life". This was felt to assist in the interpretation of scores from the AQLQ, but the authors conceded that items important to some people may have been excluded. In contrast the impact method's categorisation of items into domains relies exclusively on clinical sensibility.(385) The difficulty is that items that may be listed as important by some patients may not relate to any other items in the measure, making interpretation both for individuals and groups problematic. The lack of standardised items may also be a factor in the signal-to-noise ratio achieved. (351)

Few studies have compared these two approaches to scale development. Ware found that the individualized approach rarely yielded activities not covered by the standardized measures. (351) Juniper et al reviewed the original data used to select items for their Asthma Quality of Life

Questionnaire (AQLQ), and reanalysed them using the factor analysis techniques used by both Hyland (LWAQ) and Marks (AQLQ-M). The different approaches to item reduction led to "appreciably different instruments". (385) They found that the impact method resulted in a 32-item instrument and psychometric analysis in one with 36 items, with at least 20 items common to both instruments. This commonality would increase if fixed items were included in the 'activities' section, as the commonest activities selected by patients would form a single factor. The psychometric approach discarded the highest impact emotional function and environmental items and included in their place lower impact items mainly associated with fatigue. The domain structure created for the AQLQ was similar for both methods.

The significance of this is unclear. Tiredness or lack of energy is a major problem for asthma sufferers. It has a large social impact and is related to such problems as sleep disturbance and general limits on physical activity. (32,215) As Okamato et al showed, improvements in vitality or fatigue may be slow to manifest to patients. (372) It is conceivable that this is an area of underlying importance that may be of great significance to quality of life assessment over time, but does not readily come to mind when considering immediate asthma impact. Fayers and Hand have argued that exploratory factor analysis is inappropriate when measures contain many items dealing with symptoms and treatment side-effects, as these are 'causal indicators'. (387) These items may cause impairment for those experiencing them but the reverse does not necessarily apply, those with low quality of life do not necessarily have this symptom or side-effect. The authors argue that for these types of items breadth of coverage is crucial, and that exploratory factor analysis has less to offer. (387) For these type of items the impact method would provide more comprehensive coverage. However as asthma symptoms tend to be described in a relatively small number of ways (388), this may not be such a major issue in asthma quality of life instruments. Further, the problem that more narrowly focused functional status measures with fixed items often have is that some items may not be applicable to all subjects. For example middle-aged males may not find items dealing with cooking or ironing relevant. One solution, used by the AQLQ-M, is to

combine highly correlated items of similar difficulty into a single item, eg walking uphills and heavy housework. (382)

To date there has not been a study that tests the measurement properties of all the instruments developed using the two strategies. Rutten-van Molken et al compared the performance of the Juniper AQLQ and the LWAQ and found that the two scales showed high cross-sectional correlation, but that the Juniper AQLQ was more responsive to change and showed greater validity. (332) This difference was particularly marked for the activities domain of the Juniper AQLQ, which maybe because 5 of the 11 items in this domain are individualised or 'patient-specific'. Also, the greater responsiveness of the Juniper AQLQ may result from "informed administration", in that patients read their previous answers just before answering the questions at follow-up. Finally, the Juniper AQLQ uses a 7-point Likert response scale, while the LWAQ provides only a range of 3 possible responses, plus a 'not applicable to me' answer. (339) Thus it is possible that a number of factors related to administration rather than item selection are largely responsible for the increased responsiveness of the Juniper AQLQ. It has been shown that individualisation is not a prerequisite for responsiveness: the SGRQ has been demonstrated to be responsive to changes in a clinical drug trial. (377) Ware and colleagues found the Marks AQLQ to be more responsive to change than an individualized asthma-specific scale of activities limitations based on the Juniper method. (351) No other comparative studies have been done with the Marks AQLQ and full scales of other instruments. A minor modification to this scale which may potentially increase its responsiveness is to change the response options to a 7-point Likert scale, similar to the Juniper AQLQ. Some data exists to suggest this will ensure that relatively fine gradations of change will be detected. (340,343,389,390)

The question of whether it is appropriate to average scores across different scales such as emotional and physical function is controversial, and a considerable body of literature has sought to address this issue. (340) Weighting systems have been applied to some instruments, although, of the current asthma disease-specific questionnaires, only one uses weighting

procedures for overall scoring. (345,346) Each of the questionnaires can be analysed separately for each domain, and investigators have opted for unweighted scoring to avoid complexity. (343) There may also be advantages in analysing clinical trial results in terms of construct sub-scales and domain sub-scales in providing different kinds or information. A number of studies have shown differences in constructs and domains in their sensitivity to change. (332,334,342,344) Other workers have argued that by weighting items by the degree of distress of that problem and then aggregating scores from all weighted items, a more accurate view of overall impairment is obtained. (391,392) One study which compared weighted and non-weighted versions of an asthma specific scale found no differences between the results with weighting. (393)

A problem with weighting lies in attempting to incorporate the diverse perspectives of patients, physicians, other health workers, administrators, and regulatory agencies into determining appropriate weights. Patients, health professionals and normal volunteers often do not agree well on the importance of functions. (394,395) Patients with chronic conditions consistently rate functional items as less important than normal volunteers, suggesting they have to reappraise values considerably during the transition from non-disabled to disabled. (396) Calculating an 'average' weighting system when developing new questionnaires in unlikely to be representative of the views of any group.

Construct validity of a measure assesses whether there are plausible associations with other health related factors which seek to measure disease severity. (316) Marks et al found weak but significant correlations with physiological measures of asthma severity (FEV_1, Bronchial responsiveness). There were moderately strong correlations with the number of asthma medications being taken. In a further study the authors reported that changes in the AQLQ-M score were moderately correlated with changes in symptom scores and with change in bronchial responsiveness, and weakly with peak flow variability. (342) Interestingly, the sub-scale in which change in the measure was most strongly correlated with change in the markers of asthma

severity was the Social sub-scale, which measures restrictions on social life and sport and feelings of underachievement because of asthma.

The Juniper AQLQ has been shown to have good face validity, reliability and the responsiveness to identify differences between severity groupings and within-patient score differences over time with clinical interventions. This sensitivity to small changes has been usually evident only in the symptom and activity limitations domains of the scale. (343,344,349,358,397) In addition to the personalised activities in this instrument, this finding may reflect that the trials reporting these results were relatively short-term, clinical drug trials where the intervention is chiefly aimed at reducing symptoms and improving lung function. It may also reflect the position of Hyland's research group who feel that a 'problems' or 'knowledge' construct is more amenable to change with drug treatment than the 'evaluations' or 'appraisal' construct where people subjectively value the emotional impact of asthma. (333)

Interpreting change scores on Quality of Life surveys

The correlation between asthma quality of life measures and more traditional measures of asthma severity raises the question of what additional information such questionnaires provide. Jones has suggested that they may provide a way to score the overall change with treatment, and to address the question 'Is the improvement worthwhile?'. (341) The ability to make sense of the results, or "interpretability" remains elusive. (389) The clinical significance of quality of life changes is hampered by a lack of a clear definition of the concept of clinical meaningfulness. The novelty of quality of life measures and the inexperience of both researchers and clinicians means that users have not developed the same level of intuition about them as they have with common clinical measures. (398)

Jaeschke et al described a meaningful difference or the 'minimal clinically important difference' as the "smallest difference in score.....which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's

management". (390) Whilst this has the advantage of focussing on the patient and the clinical context, it does not suggest an operational definition for practical use. Lydick and Epstein have reviewed the interpretation of quality of life changes and various methods of providing clinical meaning. They have divided these methods into two broad categories, termed distribution-based or anchoring techniques. (398)

Distribution-based interpretations are those based on the statistical distributions of the results obtained from a study. These are commonly cited as effect sizes which compare the magnitude of the change to the variability in baseline or untreated subjects. (324,389,399,400) Guyatt et al have argued that this more a measure of responsiveness and will underestimate the minimal clinical important difference. (389) Anchoring techniques seek to relate changes in the domain scores to other clinical changes or results. The most accepted method is to compare the survey instrument with changes in a global or overall question. The clinically meaningful differences can be expressed as changes in the total score or as changes per item. This approach has been used by Juniper et al to determine the minimally important change in scores for their asthma quality-of-life scale (AQLQ). The minimally important clinical difference has been shown in two studies to be a change of 0.5 per question (on a scale from 1 to 7) (344,349,397) These findings can be compared to other chronic disease such as arthritis. On the Stanford Health Assessment Questionnaire (HAQ), Redelmeier & Lorig found a change of 0.2 (on a scale of 0 to 3) was sufficient to represent a difference in disability which was important to individual patients. The threshold for less disabled subjects tended to be lower than for more disabled patients. (401) Jones et al have found that estimated the differences on the SGRQ that correspond to a clinically significant difference in health between two populations of patients as determined by physician-based criteria. These are of similar magnitude to the changes in SGRQ score over time that correspond to patients' perception of an important change in their health. (377,402)

However, the significance of which specific global question is asked has not received much attention. Barber et al investigated the impact of two different

global questions on the interpretation of clinically meaningful change on the AQLQ. (403) One question assessed the change in the subjects asthma since the start of the study, the other how well their asthma was controlled. Each question led to a different definition of what constituted meaningful change, with anchoring to the change in 'Asthma Control' larger than the minimal perceivable improvement when anchored to 'Change in the patient's asthma'. This implies that patients may perceive a small improvement in a domain as a clinically important change in their asthma, but require a larger change in the domain to feel there has been an improvement in their control. The authors also reported that the absolute value of the minimally perceived improvement was different from the minimally perceived deterioration. This differs from the findings of Jaeschke et al and Juniper et al who have found that the distribution of change in scores on their tools was symmetric. (390,397)

An alternative approach to anchoring was reported by Brook et al who correlated observed life events with changes on a quality-of-life questionnaire. (404) Prediction of future outcomes is another possible anchor (249,405,406), but this has been an issue largely ignored in asthma research.

Others have attempted to analyse the problem of interpreting change scores of ordinal measures in clinical or research settings. (407,408) Health status scores usually have been treated as continuous variables with ratio or interval characteristics. However, there is no absolute definition of the zero point or worst health, or a natural upper limit for health. The potential for floor and ceiling features to be seen thus exists, and has been reported to be large in some populations. (316,361,407,409) Furthermore, the spacing of individual scale items and of responses, in order to achieve equal spacing of item difficulties, is rarely achieved with theoretically and empirically-based methods of scale construction and validation. Thus, most scales cannot be automatically said to have interval characteristics. On ordinal scales, the difference, say between 10 and 20, cannot be assumed equal to the difference between 20 and 30. (407) In addition, there is the difficulty this causes in interpreting change scores. Considerable debate has surrounded

the potential dangers of assuming interval properties, with perhaps less empirical research on the question. (361) Purists argue that a linear relationship must be demonstrated before interval scoring can be performed, and that "errors of inference ....must be denounced". (410) Others adopt a more pragmatic view and assert the errors produced by analysing data from scales as if they were interval do not introduce significant bias. (316,361,411)

HRQL instruments have been based on and evaluated in terms of true-score measurement theory, where recorded values are considered to consist of the true value and random measurement error. (314,316,361) Challenges to the appropriateness of the summative scoring model used for most HRQL scales, such as the SF-36 have recently been made. (412) These focus on conceptual limitations which include the lack of an explicit, ordered continuum of items that represent a unidimensional construct, such that items progress hierarchically from easy to difficult across the range of patient performance and that maintain a constant difficulty order for all patients. The lack of additivity of rating scale data, usually taken from ordinal raw scores which do not achieve interval characteristics (i.e. the distances between scale points is not uniform), is a further limitation.

Some authors have suggested that advantages may be gained if instruments were examined in terms of item-response (IRT) or latent trait measurement theory. (314,413) This approach has been used to develop asthma severity ranking scales, but has not been used in asthma patients to assess quality of life scores. (414,415) 'Latent trait' refers to the consistency of a persons' responses to the items in the scale. Performance on a test item depends on the 'amount' of the trait the person has, and that the underlying dimension may be estimated by the individual's responses to a number of items. (361,413,414) This method shows where each patient is located on the measurement scale, and where each item or question fits along the unidimensional continuum of the underlying dimension (eg quality of life). (316,361,413,414)

IRT makes more explicit the relationship between the measurement process and the underlying dimension or trait being measured. (416). Item-response provides a method to assess whether a scale has interval properties, and whether an individual is giving idiosyncratic responses (316).(417) The aim is to produce a calibrated, hierarchical scale of the underlying dimension which is at the interval level of measurement. A unidimensional index represents a single, dominant construct, even though multiple attributes may be included in the set. (408) IRT allows examination of the relationship between responses to individual items and the responses to other items in a domain. (418) The same scale is used to obtain a measure of the difficulty of an item (together with an estimate of the measurement error associated with the item) and to obtain a measure of the ability of a person (together with an estimate of the measurement error associated with the person).

The simple formulation of item response theory, designated the one parameter model, assumes that items differ only in difficulty. Two and three parameter models, which allow items to vary in their ability to discriminate and account for guessing, have also been proposed and used for research and scale development. Item response theory is not a complete alternative to the traditional theory, which has demonstrated its robustness in practical use over time, nor is it free from conceptual problems such as those discussed by Goldstein & Wood. (419) The disadvantages of item-response have been stated to include the large sample sizes needed to develop the scale, the requirement for unidimensional concepts, and the assumption that item parameters are the same across samples. (361,413) Classical test models are based on assumptions that maybe easier to meet in real test data. For instance, it is only necessarily to assume that the factor structure, whatever it is, is common across parallel forms. The strict requirement in IRT models for unidimensionality, and the very large samples needed to select and test items with the higher level models have been cited as potentially significant limitations to widespread application. Few studies have as yet examined the application of IRT models to quality of life data.

The components for measurement in item response theory are considered to be the encounters between persons and items; that is, where a person of a given ability encounters an item of a given difficulty. The model for item response theory assumes that the probability of a person obtaining the "correct" answer to an item is a function of the difference between the ability of the person and the difficulty of the item. When the data fit the model, items are positioned along the measurement continuum according to the difficulty they present patients, and patients are positioned according to the ability demonstrated with regard to the items. Thus, the person ability and the item difficulty are both measured on the same calibrated scale. The overall validity of an item is obtained by summarising the probabilities over persons for that item. The overall validity of a person's responses is obtained by summarising the probabilities over items for that person. The basic equation is a logistic function given by the equation:

$$p(x_{ni}) = \exp(b_n - d_i) / [1+\exp(b_n - d_i)]$$

where

b_n = the metric position of the ability of person n on the scale

d_i = the metric position of the difficulty of item i on the scale

and the probability of a correct response equals 0.50.

This basic IRT equation can be represented by an item characteristic curve which is more informative than conventional measures of item performance. (418) This curve shows the probability of obtaining a particular response on an item for persons across the range of ability. If the probability of responding positively to an item increases as a function of an increase in the latent variable being measured (e.g. health-related quality of life) then this item is behaving properly. In addition, the rate of change in the probability of endorsing an item indicates the degree of effectiveness of an item between any points on the latent variable, in estimating changes or differences in the latent variable.

The focus of item response theory is on the individual items, and not on the test as a whole. In the estimation process, the influence of the particular group used to calibrate the scale is minimised by adjusting for the mean

ability of the calibration group and the spread of ability within the group. The score for a given person does not depend on a particular set of items, which also facilitates the estimation of ability where a person has missing data on one or more of the items. The "ability" of a person is given by the location of that person on the calibrated scale. The magnitude of the accuracy is measured by the measurement error, estimated for each person. The unidimensionality of the scale may be assessed by overall fit statistics, and the fit of each item examined. The fit of each person may be assessed, indicating the predictability of the pattern of responses by that person.

IRT models meet the conceptual requirements of order and additivity. Thus, a particular score using an IRT model means that the person has progressed to that point on the range of the scale, as defined by those items of that scale. In contrast, using the summative model, the same score indicates the person has progressed through a certain number of items on the scale, although not necessarily sequentially. The expected differences on aggregate scores between the use of a Likert summative score and the transformed IRT measure have been summarised previously. (416) Equal differences in the raw score will not represent equal differences in the transformed score. A plot of the two scores is expected to form an ogive (sigmoid) shape in which the curve rises gradually, has a steep central shape, and then gradually flattens out. This indicates that the scores do not form a linear relationship, and that the IRT scores at the ends of the range are more spread out than the corresponding Likert scores. The IRT scores can thus be expected to be more precise at the extremes of the range of quality of life.

Recently, a number of scales used in the field of rehabilitation medicine have used IRT methods in development and validation. The Physical Functioning scale of the SF-36 has been examined using Rasch analysis to determine its scale properties. (408,418) The overall scale model has been found to not be linear. Intervals between items at both extremes of the scale were greater than for items in the mid-range of the scale. (407,418) The interval scale provided by the model showed a concentration of items reflecting moderate difficulty, with narrow spacing in the mid-range of the scale, where a particular

difficulty level is often represented by two items. This tended to inflate numerical gains for patients with moderate difficulty compared to those with very severe or minor physical disability. This phenomenon was also reported by Haley et al, who found similar features on the same physical function scale of the SF-36. (408) Stucki et al reported the calibration of the relevance of change scores using the external standards of patient satisfaction and self-perceived change in function. They found that patients with worse initial health required larger numerical gains than patients with better health to perceive improvement in function and to be more satisfied. These findings suggest that interpretation of change scores of ordinal scales require consideration of baseline health status, and that numerically equal gains may differ in their meaning depending on baseline health. Some authors have suggested that statistical adjustment for baseline values offers a simple method for taking account of case mix in general or diverse populations, but this approach needs testing. (381)

The relative precision of the Rasch scoring method compared with usual scoring was also greatest in discriminative comparisons of groups at either ends of the scale. (418) Rasch analysis of the Health Assessment Questionnaire (HAQ) and the SF-36 in subjects with arthritis has shown these scales are not equidiscriminating, and that a person's change in summed score will be more of a function of where they started, rather than on how much they have changed on the underlying dimension. (328,407)

These studies have been done using patients with rheumatoid arthritis, and on the Medical Outcomes Study population, which although a large patient sample, contained only small numbers of defined persons with asthma. Thus, it remains unclear whether patients with asthma respond to the PF-10 of the SF-36 in a similar manner to these groups. Further, these studies used the Rasch rating scale model, which assumes that each item has a similar pattern of difficulty associated with the three-point rating scale. As Stucki and colleagues have suggested, there is no rationale to assume equal meaning of changing from "limited a lot" to limited a little" and from "limited a little" to "not limited at all". It also cannot be assumed that these steps have equal

meaning for different scale items. The use of the partial credit model, which makes no a priori assumption of the similarity of scale points across items, can test the accuracy of this assertion. No analysis of asthma HRQL scales has been done using the IRT methodology.

These results would suggest that the amount of change judged to be clinically significant will vary for different populations, depending both on baseline health and on the particular anchor used to give context to the 'meaningful' change. This applies to the situation the tool is being used, so that the change measured to assess the impact of an intervention on a population will be different from that of individual clinical significance. (398,420) Factors such as the 'rebound effect', where people exaggerate well-being when recovering from serious illness, indicate the complex interrelationship between the role played by various 'psychosocial assets' which have an impact on the experience of life, and their contribution to the rating or scoring of quality of life. (421) If health-related quality of life is considered an outcome, then factors which may explain the variance in this outcome, such as self-efficacy, self-management behaviour and coping styles, need to be elucidated.

Influences on Quality of Life survey scores

Quality of life instruments typically focus on problems and dysphoric states associated with illness. These are evaluated as deviations from standards, which are normative concepts usually determined by the investigators. (338) Research into life satisfaction shows that measures of negative life satisfaction are relatively independent of measures of positive life satisfaction. (422) Negative evaluations of events and negative mood, rather than positive evaluations and moods are predictors of somatic complaints. (423-427) Hyland has proposed a model of health-related quality of life constructs which includes a construct of positive evaluations. It postulates that positive evaluations of health are not merely the absence of health problems, but positive ways in which illness has contributed to the patient's life. (315) The Satisfaction with Illness Scale was developed to measure evaluations of

positive consequences of illness. In a sample of patients with COPD the scale correlated with another scale of positive life satisfaction. The pattern of correlations suggested that the scale primarily tapped into the positive learning experiences which arise from physical illness. (422) Possible reasons why illness may have positive consequences include the re-evaluation of life and loved ones, others may find illness useful for manipulative reasons. Negative evaluations of health correlate differently with personality than positive evaluations. Negative evaluations correlated with neuroticism, whereas positive evaluations correlated with extroversion. Patients were more likely to view their illness positively when they recognise that they are seriously ill, although this was not a universal trait. (334) The relationship between the concept of illness satisfaction and other aspects of coping with asthma has not been closely examined.

Mood state, specifically anxiety and depression, has been reported to be associated with perceived health-related quality of life in patients with asthma and COPD. (346) Okubadejo et al found anxiety and depression correlated with SGRQ scores in COPD patients. (2) Other studies have shown that in COPD in general, psychological factors have been better predictors of quality of life scores than physiological parameters. (3,4) The significance of age, socioeconomic status, social support and coping styles on HRQL in COPD has been mentioned earlier. (5-7,175) Although a number of studies have examined the effect of mental health problems in asthma, little work has been done looking at the effect on scores of validated survey instruments of quality of life. Fewer studies have examined the influence of other temperamental or personality factors on these instruments.

The impact of co-morbidity has not often been taken into account in reporting results of quality of life surveys in asthma. Ferrer and colleagues have demonstrated the significant influence comorbid conditions can have in chronic obstructive pulmonary disease. In particular, the degree of impairment reported by patients with mild airways disease was significantly greater when co-morbidity was present. (428)

Conclusion

Measurements of quality of life, that examine health in terms of what is important to patients, are increasingly used in asthma research as a means of assessing health outcomes. Issues concerning what factors influence patient responses to these instruments, and the clinical importance and meaning of change scores, have not yet been fully explored. Although the relative merits and disadvantages of various types of questionnaires has been postulated, these have not yet been well defined with data.

Chapter 3

Population description; Instruments and Statistical Analysis

Introduction

The data for this study comes from patients participating in the Western Region Asthma Pilot Project (WRAPP), an observational study of factors related to adult asthma patient outcomes over a twelve month follow-up period. Subjects were recruited from patients attending The Queen Elizabeth Hospital (TQEH), Woodville, or the Lyell McEwin Health Service (LMHS), Elizabeth, in South Australia, for management of asthma. Data was collected from patients at both sites between June 1995 and December 1997. Approval of the study protocol was obtained from institutional ethics committees.

The WRAPP project was originally designed as a controlled intervention study of the effect of protocol-driven consultations based on current international asthma clinical guidelines for use in all hospital encounters for asthma patients. Information technology (IT) solutions were to have been developed for entry and retrieval of clinical data at point of care, and to provide access to test results, graphical display of data and clinical decision support according to current management guidelines. Purpose-designed software (MCARE Asthma, Medical Communications Associates, Belair, South Australia) was developed following a tender process. Funding was provided from the South Australian Health Commission via the INFO 2000 project. Emphasis was placed on ascertaining patient concerns and goals for care and incorporating patient preferences into clinical management. The aim was to support both complex and simple decision-making. The system was designed to run in a standard Windows environment, using pen-based, mobile systems with wireless LAN communications technology for use at the bedside. The development of the software was based on attempting to translate published consensus guidelines into a workable system. Unfortunately, extensive and prolonged delays at implementing the system, due largely to networking and system compatibility issues, has meant that at the time of writing the system

was not yet operational. Consequently, the set of evaluation tools has been used to follow subjects as an observational study of hospital asthma patients, in two different settings. The Queen Elizabeth Hospital has a fully operational and specialist staffed Respiratory Medicine Unit, whilst at the Lyell McEwin Health Service care is provided via General Medical Units with one session per week from a visiting Respiratory Specialist.

Population

Subjects were recruited following attendances at outpatient clinics and emergency departments, or hospital admissions for asthma at both sites. Case-notes were reviewed to determine subject eligibility for enrolment into the study. Subjects were eligible if there was a physician's diagnosis of asthma and evidence of an increase of 15% or more in Forced Expiratory Volume in 1 second (FEV_1) after bronchodilator medication (or >200 mls if the baseline FEV_1 was 1.3 litres or less), or a Peak Expiratory Flow (PEF) rate measurement increase of more than 20% after bronchodilator medication (provided baseline PEF greater than 300 litres per minute), or PEF variation of 20% or more within a day on more than one occasion, or evidence of bronchial hyper-responsiveness with a provocative dose of histamine required to cause a 20% fall in FEV_1 ($PD_{20}FEV_1$) of less than 4 μmol. (1) All eligible, consecutive persons were contacted in person or via telephone by a non-physician research assistant to seek their participation in their study. Informed consent was obtained from all subjects. Recruitment rates for the two hospitals were 92% from TQEH and 82% from the LMHS. A total of 293 subjects were recruited to the study. Spirometry results were obtained from the medical records of patients for the day of discharge (for inpatients) and at outpatient review. The socio-demographic characteristics of the sample population are shown in Table 1, and the asthma morbidity and management in Tables 2 and 3.

Survey Methods

Following enrolment, surveys were administered at baseline and subsequently at 3 monthly intervals. The questionnaires were sent via post to all subjects. If no reply was received within 2 weeks, telephone and postal contact was made to remind subjects and address any difficulties they may have had. A further approach was made if no response had been obtained after 2 more weeks. Subjects were sent the following survey on one occasion even if no response had been made to the previous one. All questionnaires were re-administered 7-14 days after baseline (mean 11 days) to the first 67 subjects enrolled consecutively to allow calculation of test-retest reliability of the questionnaires in this population. Baseline reliabilities were calculated on the entire population sample

Population description

There was a predominance of females with 67% of subjects being female. Mean age of the population was 42 years, with a range of 15-80 years, and 55% were recruited from The Queen Elizabeth Hospital. Table 1 The majority of subjects (68%) were Australian born, most (61%) were currently married or living in a defacto relationship, and 16% were divorced or separated. Table 1 Over half (54%) received some form of income assistance from social security, 43% lived in their own house, and 46% had less than 3 years of secondary education. Table 1 A large proportion had low incomes, 32% earned <A$8,000 per year, 29% A$8-20,000, and 31% A$20-50,000 per year. Current smokers comprised 18% of the population. Table 1 The symptoms and lung function of the population indicated a relatively high proportion of subjects with moderate to severe asthma activity (Table 2,3), compared with those described in community surveys(2,3,4). The majority had FEV_1 values less than 80% of predicted for age and size, with 30% recording a FEV_1 of <60% predicted, and 40% with a FEV_1 between 60-80% predicted. Nocturnal symptoms were reported to occur weekly or more often by 77% of the population, with 19% having nocturnal awakening every night, 32% most nights, and 10% having nocturnal symptoms rarely. Relatively

intensive medication regimens were in use, with 32% reporting taking between 1000-2000 mcg/day of inhaled corticosteroids, and a further 19% taking >2000 mcg/day. Regular oral steroids were used by 14%, bronchodilators were taken 1-4 times/day by 29%, and >4 times daily by 25%. Over half (58%) had presented at the emergency room for asthma over the previous year, with 39% admitted to hospital and 65% losing days from usual activities due to asthma in the past year.

The surveys included questionnaires covering the following areas (these are summarised in Table 4, including reliability values for baseline and at the 12-month follow-up; and are provided in full in the appendix. Page references indicate an instrument's location in the Appendix):

Morbidity, including symptoms and health service use (p344-347,362,)
Medication usage (p342-343,345-346)
Socio-demographics and Socio-economic status (p351-358-360)
Quality of life (p348,352-355)
Coping styles- Avoidance/Withdrawal, Active, Denial (p349)
General Adherence (p349)
Medication Dislikes (p349)
Attitudes and knowledge of medication (p342-343)
Satisfaction with illness (p356-357)
Health as a value (p356-357)
Socially desirable response set (p357)
Social support (p361)
Self-management Autonomy Preferences (p340-341)
Physician Participatory decision-making style (p358)

Tools and Questionnaires used in the study

Morbidity

No generally accepted measure of asthma severity or morbidity is available. (5,6) In this study symptoms were assessed by frequency of nocturnal and

morning symptoms, frequency of asthma attacks, exercise limitations (modified MRC scale), as well as an overall self-rating of asthma. These items have been used and validated in the South Australian Asthma Study. (7) In the analysis, symptoms were analysed individually and also as a summed total score.

Self report management and utilisation items

Self-reported attendance at an emergency department (ED) for asthma and hospitalisations for at least one night were included in the questionnaires completed by all patients at each 3-month follow-up. For those lost to follow-up by the questionnaire, subsequent hospital admission and emergency department visits were verified by examining hospital records at The Queen Elizabeth Hospital and the Lyell McEwin Health Service. This data was not verified by comparison with records at other metropolitan hospitals due to the administrative effort required. Central records are not currently kept for South Australia for ED attendances. Each hospital in Adelaide maintains distinct patient identifying numbers, and patients are not required to attend a particular hospital for treatment in the event of an emergency. Recent evidence from Adelaide indicates self-report is an accurate method of identifying asthma hospital admissions. (8)

Respondents were asked. "How many times in the last 3 months have you had an attack of asthma that was so bad that you had to go to a hospital emergency or casualty department?". (9) Subjects were also asked, "How many times in the last 3 months have you had an attack of asthma that was so bad that you had to be admitted to a hospital ward and stayed there for at least one night?".

Other items sought information on prednisolone courses, visits to the general practitioner for asthma, and days absent or limited from work, school or usual activities due to asthma. Current medication usage, frequency of the need to buy replacement bronchodilator inhalers, and frequency of their use were also

assessed. Frequency of bronchodilator (BD) use was scored on a slightly modified version of the scale recommended by Woolcock and Jenkins. (10) This used a score from 0-4, with 0 for rarely or never used; 1 for less than weekly use; 2 for less than weekly but greater than daily; 3 for between 1-4 times daily; and 4 for greater than 4 times/day. Other management issues including cigarette smoke exposure, possession of an "asthma action plan" and its type, use of a peak flow meter, length of asthma history, effects of seasonal asthma, and a history of professional counselling or psychiatric visits, were included in the questionnaire, as were co-morbid conditions.

Lung function measures

Values for lung function (Forced Expiratory Volume in 1 second, FEV_1) were taken from measurements recorded in the patient's case-notes, taken in hospital clinics or wards. At both institutions it is recommended standard American Thoracic Society procedures and criteria are used for measuring spirometry and sporadic quality assurance audits are conducted. Separate measurements and assessments of measurement technique were not performed for this study.

Socio-demographics

The questionnaire is broad in that it aims to cover occupation, income, education, housing and demands on income created by the structure of the income unit, as well as standard demographic data. Additional questions included whether costs or concern about missing work had had prevented or delayed obtaining needed asthma care, and a further item inquiring about financial difficulties experienced over the past year. It was considered that information on all these areas was necessary to gain an adequate picture of an individual's social circumstances and on the multi-faceted notion of socio-economic status.

Quality of life instruments

The University of Sydney or Marks Asthma Quality of Life Questionnaire

The disease-targeted quality of life questionnaire chosen for inclusion in the study was the University of Sydney or Marks Asthma Quality of Life Questionnaire (AQLQ-M). This is a 20-item, fixed-format, self-administered questionnaire with Likert-scale responses developed in Australia to measure quality of life in adult subjects with asthma. (11) It has been shown to have good cross-sectional construct validity as well as reasonable longitudinal validity and responsiveness to change over time. (11,12) Initial identification of items for the scale were derived from patient focus group discussions, and clinical experience. The patient's perspective was the major focus of this process, and attention was directed towards social impairment and cognitive aspects of asthma. The final scale was constructed by selection of items by principal components analysis from responses from 283 subjects with asthma. The factor analysis identified four component domains identified by descriptive labels referring to their general content. These were Breathlessness, Social, Mood, and Concerns. (11)

The AQLQ-M uses a 5-point Likert response scale. One possible way of increasing reliability and responsiveness of an instrument is to add more response points to each question. A minor modification to this scale which may potentially increase its responsiveness, is to change the response options to a 7-point Likert scale, similar to the AQLQ of Juniper et al. (13) Extending the number of steps on each item allows greater variance or spread of responses, which tends to increase the average correlation among items. (14) Some data exists to suggest this will ensure that relatively fine gradations of change will be detected. (13,15-17) The 7-point Likert scale has also been shown to comparable with visual analogue scales. (18) The validity of the modified AQLQ-M using a 7-point Likert scale (MAQLQ-M) thus needed to be established.

Two items in the Breathlessness sub-scale of the original AQLQ-M had two indicator activities combined together in order to form single items. This was based on similar factor analysis values obtained for 1) 'I have been restricted in walking down the street on level ground because of asthma', and 'I have been restricted in doing light housework because of asthma', and 2) 'I have been restricted in walking up hills because of asthma', 'I have been restricted in doing heavy housework because of asthma'. Some evidence suggests that individuals may have differential responses for activities within an item, leading to ambiguous responses. (79) This may be more of a concern in populations with greater disabilities than in general populations. (79) To examine if this was an issue, the activities within these two items were presented separately, in order to re-evaluate the factor analysis values, and to examine goodness-of-fit scores using item-response theory scoring. The MAQLQ-M thus contains 22-items (Appendix p355).

Individual items in the MAQLQ-M are equally weighted and no items are transformed. The questionnaire is analysed directly from the scores recorded and the range on the modified scale is from 1 to 7, with 1 being the minimum score indicating severe impairment, and 7 indicating least impairment. The previously reported AQLQ-M scoring system orients all items so that a lower score represents better health (11). To make comparison with SF-36 (19) easier, and to assist in intuitive interpretation of the scores, the scoring system has been reversed for the MAQLQ-M, so that higher scores represent better health. (20) The domain scale scores of the MAQLQ-M are the mean of all the item scores for that domain (out of seven). Hence all domain or scale scores are expressed as a score from 1 to 7. The TOTAL or overall score is estimated from the mean score for all the items.

SF-36

The Short-Form 36 (SF-36) Health Survey was developed in the US as part of an effort to find the optimum trade-off between breadth and depth in a general health status measure. (21,22) It was designed as a generic health

indicator to be applicable to a wide range of types and severities of conditions. It consists of 36 items grouped into eight scales that measure both physical and mental concepts of health in several different ways (see Appendix for the authorised Australian version). (19,23) These include measures of behavioural functioning, emotional states, social and role functioning, as well as perceived subjective well-being. Extensive validation has been done for the SF-36 on numerous populations around the world, including Australia. (24-26) The developers of the SF-36 have reported that a large proportion of the reliable variance in the eight scales of the survey is accounted for by two components derived from factor analysis comprising physical and mental dimensions of health. (27) These are labelled as the Physical Component Summary (PCS), and the Mental Component Summary (MCS).

Scores for the SF-36 have been calculated in the standard manner (19), and for the PCS and MCS scales using the methods described by Ware and co-workers. (24) The SF 36 Component Summaries are scored using norm-based methods. The means, standard deviations, and factor score coefficients used in scoring come from the general population. A linear T-score transformation method is used so that both the PCS and the MCS have a mean of 50 and a standard deviation of 10 in the general population. Therefore each one-point difference in scores has a direct interpretation as one-tenth of a standard deviation. Norms used are for the South Australian population in 1995, obtained from the SA Spring Health Omnibus Study. (28)

Coping

Many different types of coping strategies for managing problems have been identified. (29,30) From the literature, two ideas appear central to the understanding of coping: one is variously termed approach, active, or problem-focused, the other avoidance or emotion-focused. (29-31) These

are metaphors for cognitive or emotional activity that is oriented either toward or away from stress or problems. (31) These two themes are appropriate ones to examine when considering asthma self-management and health behaviour. Asthma self-management programs promote an active approach to dealing with the condition, focusing on taking control by a variety of actions. An alternative approach, characterised by denial, has been associated with delays in seeking treatment in acute attacks, and may be a barrier to appropriate self-management. (32) The influence of these coping strategies on chronic health behaviour or on health outcomes in asthma is less clear. A number of scales developed to measure coping have been reported in the literature. (33)

Avoidance/Withdrawal, Active, Denial

To assess the relationship between coping and asthma outcomes, measures of three methods of coping with health problems were included in the study. Avoidance coping measures assessed strategies of both a predominantly behavioural nature (eg made myself feel better by eating, drinking or smoking), and of a predominantly cognitive nature (I have hoped for a miracle to make me better). Similarly, active coping strategies measured included predominantly behavioural (eg I have become more informed about my asthma.), and cognitive strategies (eg I thought about what I needed to do for my asthma). The measures of avoidance coping strategies were taken from scales used by Sherbourne et al in the Medical Outcomes Study (MOS), who had adapted them from Billings and Moos. (30,34) This study showed that avoidance was an important predictor of self-reported adherence to medical recommendations in the MOS. In the MOS, both 6-item scales had internal consistency values of around 0.7, as measured by Cronbach's alpha coefficient. (34) Response options for each item ranged from "all of the time" to "none of the time". Scale scores were then constructed by taking the average of an individual's scores for each item in the scale.

The third coping style studied was that of denial. Findings of high denial scores in patients with severe or life-threatening asthma in a number of reports from differing countries indicates it is potentially a key concept in understanding the psychological aspects of severe asthma. (32,35,36) As used in these studies, denial is a concept developed by Pilowsky and Spence in their work examining maladaptive responses to illnesses. It is described as a "tendency to deny life's stresses, and to attribute all problems to the effects of illness". (37) There has been little work examining the influence of denial on patient samples with a broader range of asthma severity. The scale contains 5 items, with a score of 3 or more items scored positively indicating significant denial. In this study, to minimise the number of inaccurate classifications of borderline responses as denial, the items were administered using five response options and only the extreme responses were scored as indicating a denial response.

Satisfaction with Illness

Research into life satisfaction has shown that measures of negative life satisfaction are relatively independent of positive evaluations of life. (38) Hyland has proposed that a more complete model of quality of life should include a construct that measures the positive consequences for patients that may be attributed to illness. (39) Hyland and co-workers have developed a tool they named the 'Satisfaction with illness' scale to measure an individual's positive evaluations of their illness. (38,40) This tool showed acceptable convergent validity with other measures of life satisfaction, and adequate internal consistency in COPD patients. (38) These authors showed that positive evaluations correlated with extraversion but not neuroticism in asthma patients. (40) They found evidence to suggest that positive evaluations was an independent construct HRQL judgements in people with asthma, warranting further examination in its relationship to scores on HRQL instruments. (40) The Satisfaction with Illness scale is a 6-item measure, where subjects respond to a 7-point Likert scale anchored by strongly agree and strongly disagree. (38)

Health as a Value.

The concept of the value placed on health is important in several different approaches to the study of health behaviour, particularly in areas of self-management or preventive health behaviour. (41) The relationship between health value and asthma self-management and asthma health outcomes has rarely been directly studied. Lau and colleagues developed a short 4-item Likert scale designed to measure the value placed on health. It is scored on a 7-point Likert scale anchored by strongly agree and strongly disagree. (41) They reported internal consistency values of between 0.63 and 0.73 across a variety of populations. Using this scale, they indicated that programs designed to change health beliefs will succeed in producing changes in health behaviours only among participants who value health highly. (41)

Socially desirable response set.

Self-report measures of attitudes and behaviour have been criticised because some people may bias their responses to be more socially acceptable, and present themselves in the most favourable light. (42,43) Hays and colleagues note that self-report represents a combination of factual self-disclosure and self-presentation to others. (42) To avoid the lengthy and burdensome socially desirable response set measures previously used, they developed a 5-item Socially Desirable Response Set measure (SDRS-5). (42) This had an internal consistency reliability value of 0.68, and a one-month test-retest reliability of 0.75 in a sample of older adults. (42) To minimise the number of inaccurate classifications of borderline responses as socially desirable, the items were administered using five response options and only the extreme responses were scored as indicating SDRS. The SDRS-5, Satisfaction with Illness Scale, and the Health as a Value scale were presented together in the survey, as they appear to tap into the respondent's relationships with others.

Social Support

The effects of social support on mortality and overall health status are well established. (44) Appraisal of social support has been found to be a predictor of emergency room visits. (45) The effects of social support on reported health are complex, involving illness and coping behaviours. (46) These effects were potential influences and confounders in this study.

Seven items were used as indicators of social support in the study. These had been previously used in the Alameda County study in the US, and the 7-year longitudinal follow-up study of Australian elderly. (47,48) Three indicators of emotional support were used: having someone to confide in, having someone who makes you feel needed, and having someone with whom you share common interests. Social participation was indicated by four items: having someone come to visit, going out to visit others, going on outings and social gatherings with others, and attending clubs and other social gatherings or church groups. A composite measure of social support was constructed by assigning each positive answer a score of 1, and each negative answer, a score of 2.

Medication Dislikes.

Much of the work on patient attitudes towards asthma management has focused on acute attacks, with attitudes toward regular preventive medication only recently attracting attention. In particular, attitudes towards medications have not often been included into research into asthma self-management and asthma health outcomes. It is sometimes assumed that patient's will be less accepting of prophylactic medicine than of medication from which they gain immediate relief from symptoms, although there is little data to support this contention. (49-51) In order to assess the emotional impact of the effect of asthma on attitudes, Osman et al measured a number of asthma "dislikes". (52) The dislike of medication cluster of items had good scale reliability with a Cronbach alpha coefficient of 0.77. They reported finding a general cluster of

anti-medication attitudes, independent of whether the medication was used for prevention or relief. These attitudes were not related to dislike of the effects of asthma or perception of interference from asthma. (52) The relationship between medication dislikes and quality of life has not been previously explored. A four item scale was used: dislike of taking medication everyday, dislike of taking oral prednisolone (steroid or cortisone) tablets for asthma, dislike of taking an inhaled steroid (preventer) medication for my asthma, and dislike of using medication such as inhalers in front of other people. Responses were scored on a 7-point Likert scale ranging from "all of the time" to "none of the time".

Adherence

Patient adherence to medical treatment and recommendations has been assessed in three primary ways in the literature. (34) These include self-report, collateral reports, indirect clinical observations (including drug level assays), and electronic devices which can measure medication usage. (53,54) The tendency of patients to respond in a socially desirable manner limits the accuracy of self-report measures. (54) The accuracy of collateral reports is a function of familiarity with the patient. Direct observations tend to be expensive and cumbersome, and they may promote an adversarial relationship between the researcher and the patient (34,55), and the cost of electronic devices was beyond the scope of this study. Because of the complexity of measuring this difficult area of adherence, multiple self-report measures aimed at detecting various aspects of medication usage by patients were used.

A 5-item measure of general adherence that was used in the Medical Outcomes Study, summarised information about the patient's typical tendency to adhere to medical recommendations. (34) Responses were scored on a 7-point scale ranging from "all of the time" to "none of the time".

Adherence to specific asthma medications was examined by a number of items, including, "Some people decide, for all sorts of reasons, not to take prescribed medications. Are there any prescribed medications that you have decided against taking?"; "How often do concerns about medication side effects prevent you from taking asthma medication?"; "Do you think you take your medication as your doctor prescribed it?"; "Do you think any other medications, therapies or techniques are useful in controlling your asthma (eg herbal medicines, breathing techniques)?"; and "We can all forget to take medication. Do you ever miss a dose of your preventer puffer?". To assess the effect of knowledge and beliefs on adherence, items were included on "Which medications do you think are useful in controlling your asthma?", and on knowledge of when to take prescribed inhalers and whether a demonstration on how to use inhaler devices had ever been provided.

Although the accuracy of self-report is generally modest, some features of study designs and of measures used in this study can improve its accuracy. (56) These include couching questions in non-judgemental terms and asking specifically about different uses of medication and attitudes toward medication. Low demand characteristics of the survey design, with self-administered instruments and patient's point of contact with non-clinical staff only, can lower the perceived need to make desirable responses. (58)

Autonomy

Although consensus guidelines for asthma management have emphasised the importance of enhancing patient self-management in asthma through increased autonomy in decision-making, little research has been done to ascertain the patients' attitudes to this management approach. Even less work has sought to examine the factors that may predict or influence these attitudes.

Ende and colleagues developed the Autonomy Preference Index (API) for use in measuring patient preferences for decision-making autonomy in a

variety of settings. (57) The index was constructed using first a modified Delphi technique, then with field testing and patient review to ensure content validity. The decision making scale consisted of six general items and twelve items related to one of three clinical vignettes, representing different clinical levels of illness severity. Mild illness was represented by upper respiratory tract illness, moderate disease by hypertension, and myocardial infarction for severe or threatening disease. Test-retest reliability for the decision making scale was 0.84 (Pearson product-moment correlation). Cronbach's alpha coefficient for internal consistency reliability was 0.82. Concurrent validity of the scale was established by correlation with an empirically related global item appended to the survey. Responses to this item correlated significantly with their decision-making scores. Convergent (criterion) validity was measured by administering the index to a selected population of diabetic patients identified by staff to be highly motivated and adept at self-care. This group scored significantly higher than the general study population. (57)

Gibson and co-workers adapted the API to make the content specific for use in asthma. (58) Their decision-making questionnaire consisted of 6 general items and 12 items related to one of their asthma scenarios-representing stable asthma, a mild exacerbation of asthma for which the guidelines would recommend medication alterations, and a severe exacerbation treated in hospital. They administered the survey to a community sample of asthmatics and also to a group of patients with asthma recently admitted to hospital. Psychometric properties of the modified scale were not reported. The results demonstrated that asthma patients did not show strong preferences for having a major role in decision-making, and that these preferences were not related to perceived quality of life. To examine if other clinical or psychosocial factors may be related to patient autonomy preferences the API, as modified by Gibson et al for use in asthma (58), was included in the survey.

Participatory decision-making style.

Evidence from other conditions indicates that patients who more actively question doctors and express opinions have better health outcomes. (28,31,32) Other authors have shown that interventions to increase patient involvement in decision making lead to better outcomes for a number of chronic illnesses, such as diabetes. (29,31) Kaplan et al studied what they describe as physicians' participatory decision-making (PDM) style, and the characteristics of patients', physicians' and of organisations' which were associated with doctors tending to involve their patient's in treatment decisions. PDM style was assessed as the aggregate of 3 items, asking the patient to rate their doctors' propensity to : 1) involve them in decisions regarding choices between treatments; 2) give them a sense of control over their treatment; and 3) ask them to take some responsibility for their treatment. These three items were contained in a questionnaire surveying patient's satisfaction with medical care, and characteristics of the visit, such as time spent with the doctor, and for what length of time the person had been seeing that particular doctor and attending the clinic. The satisfaction survey was derived from that published by the Health Outcomes Institute, 1994, with minor modifications to exclude questions relating to phoning for appointments and billing. (59)

Self-efficacy/Confidence

It has been shown that knowledge about illnesses in general, and general attitudes to health problems have not proved very useful in predicting specific instances of health behaviour. (58,60-63) Self-efficacy increases the likelihood someone will attempt a task, and may be a necessary prerequisite for a behaviour. (58,62-64) Self-efficacy has been identified as an important component of health behaviours and self-management programs. (56) Key attitudes and behaviours revolve around self-efficacy, cues to action, and cost-benefit analysis of actions. The questionnaire used was adapted from that of Schlosser and Haverman, which was developed for use in adolescents. (65)

Statistical Analysis

Data from the questionnaires were entered by professional staff into MS Access data-files and verified. Range and logic checks were performed to confirm the validity of the data. Descriptive statistics for all variables were performed in the STATISTICA statistical package. (66) The correlation of a variable with normal scores was used to estimate the Shapiro-Wilk co-efficient. The closer the correlation was to unity the more normal the distribution, and the significance of deviations from unity was tested. Categorical variables were compared in contingency tables and linear trend in proportions tested by chi-square analysis. The means of two continuous variables were compared by Student's t-test. Comparison of two scales with ordinal characteristics was done by the Mann-Whitney U-test. Relationships between two continuous variables were assessed by using Pearson's product moment correlation. Means of three or more variables were compared by analysis of variance techniques. Multiple comparisons were made by the Bonferroni procedure. All these analyses were performed on STATISTICA software. (66)

To assess the structure of questionnaire responses, factor analyses were performed using principal components analysis with rotation as appropriate. (14) Criteria commonly used to evaluate factor analysis using the principal components method were routinely applied. Eigenvalues greater than unity are required for rotation. Other criteria, previously used, including the scree test, five- percent rule, and common factor test were also satisfied. (14) Prior to the analysis a strong association was defined as a correlation greater that 0.70, a moderate to substantial association as a correlation of 0.3 to 0.7, and a weak association as a correlation of less than 0.3. (25) Cronbach's coefficient alpha value was used to estimate internal consistency reliability of questionnaires. (14,67) Helmstadter quotes desirable reliability values of 0.79 for attitude tests intended for individuals, and for ability tests of 0.90. (68) Test-retest reliability of the questionnaires was estimated by the intra-class correlation coefficient using analysis of variance methods as described by

Deyo, supplemented by Pearson correlation coefficients and *t*-tests to locate any systematic differences between the two observations. (69) For the quality of life instruments, the standardised error of measurement (SEM) is the standard deviation of an individual score and it is the most useful reliability estimate for individual-level applications. The SEM reflects both reliability and variance, as defined by standard deviation x $\sqrt{}$(1 – reliability). (67) For Chapter 6, receiver operating characteristic (ROC) curves were used as an alternative analytic strategy for evaluating constructs of change. (68,70) The method of Hanley and McNeill utilising *z*-scores was used to compare the differences in ROC curve areas. (71)

Ordinary least-squares regressions were developed using STATISTICA software. Residuals from the regressions were examined for normality around the regression by plotting the cumulative frequency distribution of the residuals against the cumulative frequency distribution for the normal distribution, and by plotting residuals against the fitted values. In Chapters 4 & 5, random effects generalised least squares (GLS) regression models were developed to examine the effects of variables on quality of life scores. The Haussman specification test was used to test the appropriateness of each of the random effects models. Random-effects models are appropriate for analysing longitudinal data when the data are continuous, normally (or near normally) distributed, and have numbers of missing observations. (72) The regression model is similar to ordinary linear regression, except that the errors of different measurements on the same individual must be assumed to be correlated. (73) The models include both overall effects, which are generally fixed effects, and within-subject effects, that are often considered to be random-effects. (72) These models assume that correlation among repeated responses arises because regression coefficients vary across individuals as a result of unobserved factors that are common to all of the responses for a given person but which, in turn, vary across people. (72,74) These models are useful when inferences are to be made about individuals. (74) The STATA statistical package was used to performed these analyses.

In Chapters 8 & 9, logistic regression models were developed using the LogXact statistical software. (75) The goodness of fit of each model was evaluated by the Hosmer-Lemeshow test, and the likelihood statistic. (76,77) The Hosmer-Lemeshow test divides all subjects into 10 risk strata. The model is used to predict what percentage of subjects in each stratum will have the outcome. This predicted percentage is then compared with the actual percentage and used in a chi-squared test. A non-significant chi-square value indicates that the probabilities predicted by the model do not differ significantly from the actual results. (78,77)

Summary

The data collected covers the four broad areas of asthma outcomes recently identified by the UK Clearing House on Health Outcomes (clinical events; psychosocial impact; self-management; patient feedback). (78) The longitudinal design with at least 12 months follow-up allows insight into the socio-demographic, socio-economic and psycho-social characteristics that influence asthma health outcomes. It has also been possible to compare outcomes between two different hospital settings with differing levels of specialist expertise available for care provision, in a non-randomised observational study.

Table 1: Socio-demographics of the study population.

(n=293)

Variable	Category	Total pop	TQEH	LMHS
Age (years)				
	Mean (SD)	42 (18)	45 (18)	40 (16)
	Median	41	47	39
	Age range	15-85	15-85	15-81
Gender (%)				
	Male	33	35	29
	Female	66	65	71
Marital status (%)				
	Married / Defacto	61	57	66
	Separated / Divorced	13	16	10
	Widowed	3	4	3
	Single / Never married	23	24	21
Country of birth (%)				
	Australia – non Aboriginal	66	69	61
	Australia – Aboriginal	2	1	2
	UK / Ireland	24	13	36
	Italy	2	4	1
	Other	6	13	<1
Income level per annum (%)				
	<$8,000	32	28	36
	$8,000-20,000	29	28	31
	$20,001-50,000	31	36	25
	>$50,000	8	8	8
Principal source of house income (%)				
	Wages	46	41	52
	Social security benefits	54	59	48
Education level (%)				
	<3 years Secondary school	46	47	45
	>3 years Secondary school	26	17	36
	Some Post Secondary	28	36	19
Employed (%)				
	Yes	46	43	50
	No / Retired	54	57	50

Table 1: Socio-demographics of the study population (continued).

Variable	Category	Total pop[n]	TQEH	LMHS
Housing situation (%)				
	Housing trust rental	36	34	38
	Private rental	7	11	5
	Living with family	14	7	20
	Own house- mortgage	27	23	30
	Own house- no mortgage	16	25	7
Private Insurance (%)				
	Yes	22	29	14
	No	78	71	86
Current Smoker (%)				
	Yes	18	17	20
	No	82	83	80
Financial difficulties over the past 12 months (%)				
	Yes	51	53	50
	No	49	47	50
Cost concerns prevented/delayed seeking asthma care past year (%)				
	Yes	41	40	41
	No	59	60	59
Concern missing work prevented/delayed seeking asthma care past year (%)				
	Yes	21	18	25
	No	79	82	75

Table 2: Asthma activity- Symptoms & Lung Function. (n=293)

Symptoms	Category	Total Pop^n	TQEH	LMHS
Self-rating of severity				
	Severe	23	23	23
	Moderate	43	41	45
	Mild	26	26	24
	No problem	9	9	8
Attack frequency				
	Persistent	22	24	19
	> Weekly	17	16	17
	> Monthly	12	16	22
	>3 / year	33	37	22
	<3 / year	15	7	17
	Never	1	<1	1
Morning symptoms				
	Every day	19	18	19
	Most days	19	19	21
	Once week	30	30	29
	Once month	7	8	6
	Never	25	25	25
Nocturnal symptoms				
	Every night	19	13	24
	Most nights	32	26	40
	Once week	26	33	19
	Once month	13	17	9
	Never	10	11	9
Exercise limitations				
	Dressing	6	4	7
	Walk on flat	11	9	12
	Hurry on flat	13	12	15
	Uphill/stairs	31	32	31
	Sport/Exercise	19	21	18
	No limitations	20	21	17
FEV_1 (% Predicted)				
	<60%	30	32	29
	60-80%	30	31	29
	>80%	40	38	42

Table 3: Asthma activity- Management

Variable	Category	Total	TQEH	LMHS
Inhaled Corticosteroid dose (mcg/day)	0	20	16	24
	1-1000	29	28	31
	1001-2000	32	36	27
	>2000	19	20	18
Regular oral corticosteroids				
	Yes	14	12	17
	No	86	88	83
Bronchodilator use				
	Never	6	10	1
	< weekly	18	16	21
	> weekly but <daily	22	18	27
	1-4 times/day	29	24	34
	>4 times/day	25	32	17
Long acting *B*-agonists				
	Yes	18	23	12
	No	82	77	88
Other asthma medications				
	Yes	44	40	49
	No	56	60	51
Emergency attendance over 1 year				
	Yes	58	57	59
	No	42	43	41
Admission to hospital over 1 year				
	Yes	39	37	42
	No	61	63	58
Prednisolone course over 1 year				
	Yes	63	66	59
	No	37	34	41
Days lost usual activities over 1 year				
	Yes	65	66	65
	No	35	34	35
Possess "Asthma Action Plan"				
	Yes	77	81	72
	No	23	19	28
Possess Written Asthma Action Plan				
	Yes	55	60	50
	No	45	40	50

Table 4: Definitions of measures used in study.

Measure	No. of items	Definition	Alpha Baseline	Alpha Follow-up	Average inter-item correl.
Avoidance coping	6	Frequency an individual uses avoidance coping in response to health problems	.83	.84	.50
Active coping	6	Frequency an individual uses active coping in response to health problems	.79	.80	.38
General Adherence	5	Patient's typical tendency to adhere to medical recommendations	.88	.87	.60
Medication Dislikes	4	Dislike of using regular asthma medications	.78	.78	.44
Satisfaction Illness	6	Positive evaluations of illness' contributions to one's life	.80	.81	.35
Health as value	6	Agreement of the primary importance of good health in one's life.	.62	.65	.29
Socially desirable	5	Tendency to give socially desirable responses	.67	.66	.29
Self-efficacy	10	Confidence/Self-efficacy in personal ability to manage asthma	.77	.79	.28
Social support	7	Perceived level of emotional support available and level of social participation.	.79	.80	.32
Autonomy	18	Preferences for decision-making autonomy regarding treatment	.86	.88	.40
Participatory decision-making	3	Tendency for treating physician to involve patient in treatment decisions.	.80	.81	.58
Total symptoms	4	Summed score of symptoms	.80	.82	.45
MAQLQ-M	22	Disease-targeted quality of life	.97	.97	.58
SF-36	36	Generic quality of life	.93	.93	.54

Chapter 4

Validity of two Health-related Quality of Life instruments in asthma.

Introduction

Management of chronic conditions such as asthma is largely directed towards symptom relief and improving quality of life. There is a growing acceptance that instruments that reliably estimate these variables are needed as outcome measures, particularly in clinical settings and as hospital outcome measurements (1). Responsiveness and longitudinal validity have been identified as the measurement properties required of an evaluative instrument that is sensitive to small changes in HRQL over time (2). Discriminative instruments which are designed to distinguish between patients in a cross-sectional survey require good reproducibility or reliability, and cross-sectional construct validity (2). A number of instruments have been developed that are capable of measuring asthma-related quality of life (3,4). As experience has grown with these tools a number of difficulties with their use have been identified. The most widely used is the Asthma Quality of Life Questionnaire (AQLQ) developed by Juniper and colleagues (5). This in part depends on each individual respondent identifying areas of their life that are affected by the disease, and measuring changes that occur in these areas. This approach has theoretical attractions (6), and using this 'personalised' tool, high degrees of sensitivity to change with drug treatment intervention trials have been demonstrated (6-8). The disadvantage of using patient-specific items is that comparing activity scores between patients is difficult as they refer to different activities. It is also difficult to compare different studies and different populations (9). Although designed to be sensitive to within-person

change, Ware et al (10) recently reported that the increased signal-to-noise ratio caused by personalising the activities scale of the Juniper AQLQ made it less responsive to within-person change than another survey tool, the Marks Asthma Quality of Life Questionnaire (AQLQ-M) (11).

In the original report by Marks and colleagues, sensitivity to improvement was adequate, although correlations with disease reference measures were at the lower end of the expected range (11). Its validity as a measure of deterioration in health status has not been fully demonstrated, hence its usefulness in a clinic setting should not be assumed (12). The reliability of the AQLQ-M when tested using Cronbach's coefficient alpha has been around 0.90 in several studies (13-15). While this is around the minimum standard required in order to use test scores to make important decisions about individual patients, 0.95 is a more desirable standard (16,17). With a reliability of 0.90 the standard error of measurement is almost one-third as large as the standard deviation of test scores. Hence errors in classification can occur if a single test cut-point is used for clinical decision making. One possible way of increasing reliability and responsiveness of an instrument is to add more response points to each item. Extending the number of steps on each item allows greater variance or spread of responses, which tends to increase the average correlation among items (16-18). So long as the response set is not extended beyond the respondents' ability to discriminate between gradations, this may significantly increase efficiency of individual items, which improves overall scale reliability (16,18), and may increase the responsiveness of the scale, as this is dependent on the standard error of measurement (16,17). However, it is possible that a test can be too stable to

reliably detect small, but real changes in quality of life (17,19). The AQLQ-M uses a 5-point Likert response scale (13). A minor modification to this scale which may potentially increase its reliability is to change the response options to a 7-point Likert scale, similar to the AQLQ of Juniper et al (5). Seven-point scales have been validated with the visual analogue scale (19), and may be more sensitive to change than a 5-point scale (20,21).

In the AQLQ-M two items had two indicator activities combined together in order to form single items ("I have been restricted in walking down the street on level ground or in doing light housework because of asthma", and "I have been restricted in walking up hills or in doing heavy housework because of asthma") (13). This combination of items was based on similar factor analysis values obtained for these activities when presented separately during the scale development (13). Some evidence suggests that individuals may have differential responses for multiple activities within an item, leading to ambiguous responses (22). This may be of more concern in populations with greater disabilities than in general populations (22). To examine this issue and to re-evaluate the factor analysis values, the activities within these two items were presented separately. Thus the instrument used in this study, the Modified Asthma Quality of Life Questionnaire-Marks (MAQLQ-M), contains 22 items and utilises a 7-point Likert response scale.

The Medical Outcomes Study Short Form 36 (SF-36) is a widely used questionnaire designed to assess a spectrum of health-related concepts. However, for an instrument used widely throughout the world in many conditions (19), there have been very few comprehensive studies demonstrating the validity of the SF-36 to assess health-related quality of life

in subjects with moderate-to-severe asthma, particularly hospital-based populations.

The validity of the SF-36 mental and physical health component summaries in individuals with moderate-to-severe asthma is not well documented. Direct comparisons between the SF-36 and asthma-specific HRQL questionnaires with regard to validity have rarely been performed. Van der Molen and colleagues reported that in a general practice population with mild asthma that for a number of relations with markers of disease severity, the SF-36 performs in the same range as disease-specific measures (23). Ware et al reported that the SF-36 was consistently less valid in discriminating between severity and responsiveness to change than the Asthma Quality of Life Questionnaire-Marks (AQLQ-M) in a sample with mild asthma. (10) No comparisons have been made on subjects with more severe impairment with regard to discriminant or longitudinal validity of the SF-36 and asthma-specific tools.

The aim of this study was to establish the validity of the modified Marks Asthma Quality of Life Questionnaire (MAQLQ-M) instrument in asthma subjects (13), to estimate the responsiveness and reliability and to establish the reliable change index for the modified tool. Comparisons were made with disease reference measures and a general health-related quality of life scale, the SF-36 (standardised Australian version 1.0) (24,25), to test the cross-sectional, longitudinal, and predictive validity of the modified scale. It was expected that the modified tool would show increased reliability and responsiveness to change, compared to that previously reported. Direct comparison of the 5-point (AQLQ-M) and the 7-point (MAQLQ-M) instruments was not made.

The second aim was to confirm the cross-sectional and longitudinal validity of the SF-36 component summaries in moderate-to severe asthma, and to compare this with the MAQLQ-M. It was hypothesised that the disease-specific instrument would show superior cross-sectional and longitudinal validity compared to the generic SF-36. Thirdly, this study compares the health-related quality of life in two populations; 1) a random representative population sample of people with asthma from South Australia (SA), and 2) the WRAPP sample recruited from clinics at two hospitals in metropolitan Adelaide, SA. Both of these groups are then compared with the HRQL for the general SA population. It was expected that the asthma subjects would show impaired quality of life that would vary by the frequency of symptoms, and would occur in the domains of physical health and to a lesser extent, if at all, in mental health. The relationship between SF-36 scores and work absenteeism for asthma in the community population is also described. It was hypothesised that SF-36 scores would discriminate between those with and without work days lost.

Methods

Survey methodology is described in Chapter 3, "Methods". Cross-sectional, or convergent validity of the MAQLQ-M was assessed by determining associations (Pearson r) with symptoms, medication use, lung function (FEV_1), self-rating of severity, global health rating, health service usage and with the SF-36 Health Survey. As the MAQLQ-M measures a range of aspects of disease activity, multivariate analyses were performed to assess this summative function. MAQLQ-M scales were used as the dependent variable in linear regression models to which a number of other measures of disease activity were added as independent variables.

Internal consistency was estimated using Cronbach's coefficient alpha value (17,26). Reliability estimates were made using the standardised error of

measurement (SEM) (26). The 95% Confidence Intervals of the SEM are an index of the random variation expected if an individual were tested repeatedly (17). Test-retest reliability was estimated using the intra-class correlation coefficient using analysis of variance methods as described by Deyo (27). This was then used to estimate the Reliable Change Index (28).

Longitudinal construct validity was examined using correlations between within subject changes in lung function (FEV1), symptoms scores and MAQLQ-M changes over three months, consistent with previously reported methodologies (6,11,13). Although the mean changes with time were small, the variation between patients in the degree to which they changed was sufficient to allow tests of association between changes in MAQLQ-M scores and changes in other measures (4). A random-effects regression model containing changes in the MAQLQ-M scores and changes in reference measures of disease activity, was estimated using the STATA statistical package. The Haussman specification test was used to test the appropriateness of each of the random effects models. Random-effects are appropriate for analysing longitudinal data when the data are continuous, normally (or near normally) distributed, and have numbers of missing observations (29). The models include both overall effects, which are generally fixed effects, and within-subjects effects, that are often considered to be random-effects (29) . These models assume that correlation among repeated observations arises because regression coefficients vary across individuals as a result of unobserved factors that are common to all of the responses for a given person but which, in turn, vary across people (29,30).

Random-effects are useful when inferences are to be made about individuals (30).

To assess if the MAQLQ-M retained the same domain structure as the original questionnaire, a factor analysis was performed using principal components analysis with varimax rotation (17). Standard criteria were used to assess the factor analysis (17). Prior to the analysis a strong association was defined as a correlation greater that 0.70, a moderate to substantial association as a correlation of 0.3 to 0.7, and a weak association as a correlation of less than 0.3 (31).

Scores for the SF-36 have been calculated in the standard manner (32,33). The SF-36 scores for the study sample were compared with South Australian population norms and with a random population community sample of persons with asthma (34), after adjusting for age, sex and occupational status using logistic regression analysis. Age was included as a continuous variable, with sex, disease status, and occupational status as binary categorical variables. Occupation was classified using the Australian Standard Classification of Occupations (ASCO) codes (35). This is a skill-based classification of occupations which is used as a national standard by the Australian Bureau of Statistics. Two levels of socio-economic status (low/medium or high/very high) were derived using a conventional method of aggregation (35). This data came from the Spring South Australian Health Omnibus Survey, which is a representative population survey of South Australians aged 15 years or more, conducted annually on a range of health issues, including asthma (36). The data from the Omnibus survey was

collected at a single point in time during October and November 1995. The sampling frame for the survey involved a multistage, systematic, clustered area sample of 4200 households in South Australia, with 75% of the sample selected from the metropolitan Adelaide area and the remainder from country centres with a population of 1000 or more. Hotels, motels, hospitals, nursing homes and other institutions were excluded. The person aged 15 years or older whose birthday was next at each selected household was interviewed person-to-person by a trained interviewer about a range of health issues. If needed, up to six call-backs were made to interview the selected person. The response rate for the survey was 72.4%, yielding 3010 interviews. The sample is selected first, by selecting a random sample of Australian Bureau of Statistics collector districts. Within each collector's district a random starting point is selected and from this point ten households are then selected in a given direction with a fixed skip interval. Because the data come from a large clustered sample they were weighted by household size, age, gender and local government area, to the estimated resident population data so that the analysis would be representative of the South Australian population. The Omnibus study method has been described previously in detail (37-39) Subjects with asthma were identified by positive answers to three questions, "Have you ever had asthma?", "Was your asthma confirmed by a doctor?", and "Do you still have asthma?", as validated in a previous study (39). Further information was obtained from those with asthma on nocturnal and morning symptom frequency, and whether they had lost days from work or school as a result of asthma in the preceding 12 months (36). Within the survey, all respondents were administered the standardised Australian version of the SF-36 (24). In order to identify where those with asthma

scored in relation to the total SA population distribution of scores, standardised scores were calculated, using the whole population as a reference (33). Standard scores were calculated by dividing the difference between the score of the comparison group and that of the general population by the standard deviation of the general population (40). In the line graphs, the mean of the population is set at zero, and the deviation from this score is measured as a standard score. This standard score also allowed the identification of the corresponding percentile of the population in which a person with asthma would fall.

The significance of the differences between two groups was tested by unpaired t-tests for parametric data, Mann-Whitney tests for ordinal data and Chi squared tests for nominal data. SF-36 scales which have definite ordinal characteristics (role function scales, pain, social functioning) were compared with Mann-Whitney tests, the other scales were analysed with t-tests.

Results

Responses were obtained from 293 subjects at baseline and from 232 persons at the 12-month follow-up, a 79% retention rate. Data was available from 254 subjects for the 3-month follow-up comparisons for the longitudinal validity analysis (86% retention). Socio-demographic and clinical characteristics of the study population are shown in Chapter 3, 'Methods', Table 1. There was a predominance of females with 33% of subjects being male. Mean age of the population was 42.3 years, with a median age of 41 years, and a range of 15 to 85 years. Fifty-five percent were recruited from The Queen Elizabeth Hospital, the remainder from the Lyell McEwin Health Service.

The details of the population with regard to symptoms and management characteristics are described in Chapter 3, 'Methods', Tables 2 and 3. These indicate a relatively high proportion of subjects with moderate to severe

asthma activity, with relatively intensive medication regimens, compared with those described in community surveys (36,41,42). Scores for each survey period are shown in Table 1. Comparison of the scores at baseline for those with and without 12-month follow-up is shown in Table 2. This indicates no statistically significant differences in scores between these two groups (p= .58), and standard deviations and score ranges suggested similar distributions of scores. There were no statistically significant differences in the two groups with and without 12-month follow-up when compared for age, gender, baseline symptoms, or household income. The 67 subjects used in the test-retest reliability study also did not differ from the full study population in terms of these criteria.

Mean scores for both the SF-36 component summaries were less than 40 at baseline, indicating significant impairment in general health status in the sample (Table 1). The standard deviations of the scores were close to 10, indicating the distribution of scores was close to normal. This was confirmed by the Shapiro-Wilk test (p = .32). One of the postulated advantages of the component summaries over the individual scales is the elimination of floor and ceiling effects on the scores. This was confirmed with the lowest scores for the PCS and MCS being 12.7 and 5.5 respectively. The upper range of scores in the sample was 60.7 for the PCS and 66.9 for the MCS. This compares with floor effects being seen in up to 30% of subjects in some individual scales (Role limitations, Physical and Emotional).

The MAQLQ-M scores showed a mean of 4.2 and standard deviation of 1.2, and with a median score of 4.3 and an interquartile range of 3.2-5.4 (Table 1). Floor and ceiling effects were rare, with less than 1% of the subjects reporting either extreme maximum or minimum possible scores. The distribution of scores was normal (Shapiro-Wilk p = .16).

Reliability

The reliability and SEM values for the MAQLQ-M and the SF-36 are shown in Table 3. Internal consistency for the MAQLQ-M was high with reliabilities that

exceeded or were within the ranges of recommended standards for use in decision-making at an individual level (17). Cronbach's coefficient α for the TOTAL scale was 0.97 and all values exceeded 0.90. The values of greater than 0.90 indicate that an estimated less than 10% of the observed variance is due to error in measurement. Table 3 indicates that individual patient scores would be expected to fall within 0.2 and 0.38 for all scales of the MAQLQ-M about 68% of the time (equal to one SEM), and between 0.4 and 0.76 about 95% of the time (33).

The average inter-item correlations ranged from 0.58 to 0.74. Item internal consistency is conventionally supposed to be satisfactory if the correlation between the item and the scale is at least 0.40 (19). For the SF-36, the PCS reliability exceeded 0.90, whilst the MCS closely approached this standard, with a value of 0.89.

Longitudinal reliability.

Table 3 presents the precision estimates for longitudinal monitoring using the Reliable Change Index. Four of the sub-scales of the MAQLQ-M exceeded the lower bound of the recommended reliability standard of 0.90, but none achieved the preferred level of 0.95. This standard is difficult to achieve in health status measures (26). It can be seen that for the TOTAL score, the 95% confidence interval of the SEM is about 0.6, and for the BREATHLESSNESS and SOCIAL sub-scales this value is around 0.7. The confidence intervals for the MOOD and CONCERNS sub-scales suggest that until a change score reaches 0.8, it is difficult to state with confidence that an significant change has occurred (28). The lower test-retest reliability and larger standard deviation of the SF-36 MCS increases the 95% confidence intervals of the SEM compared to the PCS.

Factor analysis

Results of the Factor Analysis for the MAQLQ-M are shown in Table 4. Factor loadings greater than 0.30 are reported, along with average inter-item

correlations and final communality estimates. The results showed a strong primary factor explaining nearly 60% of the common variance of items. The strongest loadings on this factor corresponded to the BREATHLESSNESS sub-scale of the original instrument, with a further 3 items having correlations >0.40 on this factor. A second factor, explaining 7% of the variance, corresponded to the MOOD sub-scale. The third factor had strong loadings from all items in the SOCIAL and CONCERNS sub-scale of the original survey. Four items of the BREATHLESSNESS sub-scale had loadings greater than 0.40 on this factor as well. This factor accounted for 6.1% of the common variance. The cumulative proportion of the variance explained by this three component solution was 72.6%. No other factors had eigenvalues greater than unity. The final communality estimates, indicating the proportion of variance of each item explained by the chosen solution ranged from 0.50 to 0.81 for all items except one ("I have been dependent on my asthma sprays"), whose value was 0.39.

The factor analysis values for the 4 indicator activities combined into two pairs of items in the original AQLQ-M, and that are presented separately as 4 items in the MAQLQ-M, are also seen in Table 4. The results indicate similar values for each of the pairs of items usually combined in the MAQLQ-M ie 1) restrictions with heavy housework and walking uphill, and 2) restrictions with light housework and walking on level ground.

Cross-sectional validity

The relation between the MAQLQ-M and some markers of asthma severity, using Pearson product-moment correlations and linear regression models, are shown in Tables 5 and 6. Stronger associations were seen between MAQLQ-M and symptom and rating scales than for lung function, medication usage, and health service utilisation measures of outcome. This was more marked for the self-rating of severity and the global health ratings than for scoring of individual symptoms. All correlations were in the expected direction, and all were statistically significant to at least the $p< 0.01$ level. The pattern of correlations showed the MOOD sub-scale was less strongly

associated with the disease reference measures than the other sub-scales. A similar pattern was seen for the SF-36 component summaries, with significant associations seen particularly for the PCS (Table 7). The PCS scale showed stronger associations with clinical measures than the MCS. The associations between the PCS and disease measures were consistently less strong than those seen with the MAQLQ-M (Table 7,8).

The MAQLQ-M and the SF-36 showed good discriminative ability for all symptom categories (Table 9). Scores showed clear trends with increasing symptom frequency for all sub-scales of the MAQLQ-M and for the SF-36 summaries. Self-rating of asthma severity and the frequency of asthma attacks showed the clearest trends with increments in scores corresponding to different levels of symptoms. For exercise limitations, those with limitations walking on the flat reported worse quality of life than those people with difficulties in dressing. Limitations walking uphill or upstairs caused similar impairment to problems with sport or exercise. There was little difference in the impairment in quality of life between weekly or monthly morning and nocturnal symptoms. Those with no exertional limitations reported better quality of life than those who were not experiencing nocturnal or morning asthma symptoms. HRQL scores were significantly greater for those with FEV_1 values above 80% of predicted compared with those with lower FEV_1 values. An even greater decrement in HRQL scores was seen for those with FEV_1 values below 60% of predicted. The pattern of responses showed that those not complaining of symptoms in each of the various categories scored around 6 for the MAQLQ-M (out of a possible 7), and around the population mean of 50 for the SF-36 Summary scales. Despite substantial proportions reporting no symptoms in any of the categories, mean scores on the MAQLQ-M for these patients were below the maximum in all scales.

Multiple regression models for the combined effect of total symptom score, self-rating of severity, daily inhaled corticosteroid dose, reliever medication usage and FEV_1, with each of the MAQLQ-M scales as the dependent variable are shown in Table 8. It can be seen that a significant proportion of the scores on all scales was associated with the self-rating of asthma

severity, and a further proportion was negatively associated with increasing inhaled corticosteroid dose. Total symptom score was the dominant correlate with the BREATHLESSNESS section, but was not significant for the other domains. Frequency of reliever medication (bronchodilators) was associated with a significant proportion of the MOOD score, but not to any of the other scales. The lack of significance of FEV_1 when entered as a continuous variable into the equations should be noted. This is because, in these models, exercise limitations accounted for nearly all of the effect of spirometry on MAQLQ-M scores, except in the BREATHLESSNESS sub-scale. For the PCS, severity rating, level of exercise limitation, and daily ICS dosage were significant parts of the model. Again symptoms and lung function did not remain significant when these other factors were included. The level of association was less strong for the PCS than for the MAQLQ-M.

The association between the MAQLQ-M and the SF-36, as assessed by Pearson r values and by linear regression with the MAQLQ-M as the dependent variable are shown in Tables 10 and 11. These show generally strong associations between the two instruments. Less strong associations were seen between the Pain and Role Limitations- Emotional scales of the SF-36 and all sub-scales of the MAQLQ-M. The BREATHLESSNESS scale of the MAQLQ-M was most strongly correlated with the Physical Functioning scale of the SF-36, while the MOOD scale of the MAQLQ-M was strongly associated with the SF-36 Mental Health scale. General Health Perceptions and Vitality of the SF-36 were closely correlated with all sub-scales of the MAQLQ-M. Vitality was particularly strongly correlated with the SOCIAL sub-scale.

Examining the SF-36 in terms of standard scores, it can be seen from Table 12 that for the scales contributing to the Mental Health Component Summary, the largest reductions in scores in the present study population compared with the general population occurred in the Emotional Role Limitations scale and the Social Functioning scale, rather than the measure of Mental Health. Reductions in the dimension of physical health occurred more uniformly, except for the minor impact of asthma on Bodily Pain.

Cross-sectional validity of the SF-36 in a population sample- Omnibus Survey.

The data from the South Australian Omnibus Health Survey was collected once from each subject during October and November 1995. In the Omnibus Study, the prevalence of self-reported current, doctor-diagnosed asthma was 9.9% (n=299). A greater proportion (16.9%) said that they have had asthma at some time in their life. Ninety percent of this group, or 15.3% of the subjects overall had their asthma confirmed by a doctor. Among respondents with asthma, 31.4% reported waking in the morning with asthma symptoms weekly or more often, 22.6% reported waking monthly or less often, 26.8% woke with symptoms only at certain times of the year and 19.2% never woke with symptoms. With regard to waking during the night with symptoms, 15.6% woke weekly or more often, 19.3% woke monthly or less often, 27.6% woke only at certain times of the year and 37.5% never woke during the night with symptoms.

Comparison of SF-36 scores between the study sample, SA population norms and with a community sample of persons with asthma, after adjusting for age, sex and occupational status, is given in Table 12. Scores for respondents with asthma in the community sample were significantly lower across all scales of the SF-36, compared with their non-asthmatic counterparts in the general population. Figure 1 shows the profile of standardised scores in a graphical display, with associated 95% confidence intervals, with zero being the general population mean. People with asthma in this community sample were worse off across all domains of functioning compared with the general population. In terms of aspects of physical functioning and mental health, they were between the 34th and 42nd percentile of the population. In terms of general health perception, they were near the 27th percentile. Arthritis and diabetes in general had a greater impact on physical health that asthma. Health perceptions were lower in people with asthma than in persons with arthritis, and social functioning was limited to about the same degree. Mental health scores were reduced to the same extent by asthma, diabetes and

arthritis. There were large differences between the Omnibus community asthma sample and the present study population, recruited from hospital clinics. For the component summaries there was a difference of 6.8 in the PCS, and 8.4 for the MCS. Comparing the present study population with the general SA population, for physical health scales such as Physical Functioning limitations and Role-Physical limitations, reductions in standardised scores of 1.1-1.2 standard deviation units were seen. This would correspond to around the 15th percentile of the population. The reduction in General Health Perceptions for the study population was greater, with mean scores at around the 10th percentile of the population.

Figures 2 and 3 show that among people with asthma in the community sample, for the four categories of symptom frequency in the morning and waking at night, there was a trend for lower scores across most of the dimensions with increasing symptom frequency. However, morning symptoms did not seem to affect functioning in a marked way until they occurred weekly or more often. Morning symptoms occurring more than weekly reduced role functioning due to physical limitations down to below that of the 10th percentile of the population. Frequent (weekly or more often) nocturnal awakening had a major impact on the dimensions of physical functioning, role limitations due to physical problems and social functioning. This frequency of symptoms reduced general health perceptions to the level of the 15th percentile of the population. The frequency of nocturnal awakening had much less effect on other dimensions, although persons with asthma had lower scores than the general population. Those who never awaken with asthma had scores very similar to the general population, except for general health perception and role limitations due to emotional problems. Of respondents with current asthma, 20.3% had lost days from work, school or home duties due to asthma in the last 12 months, with a mean number of 13 days lost, and a median of 5 days lost. This group had significantly lower scores across all dimensions of the SF-36, except role limitations due to emotional problems, compared with those who had not lost days from activities (Table 13).

Longitudinal validity

From the initial study sample of 293, some 234 respondents completed the 3-month surveys, a retention rate of 80%. The correlations with changes in the MAQLQ-M and changes in FEV_1, symptom scores and health service use over the initial 3-month survey period are listed in Table 14. These showed moderate, statistically significant correlations between changes in HRQL scores and the conventional clinical measures. Changes in symptom scores were more strongly associated with HRQL changes than were the lung function changes. Again the self-rating of severity and overall rating of change in asthma was the most strongly associated with the MAQLQ-M.

A GLS random-effects model was developed for changes in HRQL scores and changes in clinical measures (Table 15). The values for the correlations and regression coefficients between change in the MAQLQ-M and reference measures were comparable to the values obtained in the cross-sectional data.

Discussion

The results demonstrated the validity of the modified AQLQ-M and of the SF-36 component summaries as instruments for assessing asthma quality of life. The cross-sectional construct validity of the SF-36 has been reported previously (43-45), but longitudinal validity is not well documented in the literature. The validity of the SF-36 Physical and Mental Component Summaries is less well documented. This study confirms the cross-sectional and longitudinal validity of the component summaries in asthma.

The test retest reliability of the SF-36 component scores were comparable to those obtained in a previous test-retest study in a general population sample in the UK, where values of 0.89 and 0.80 for the PCS and the MCS were obtained. (46) The lower test-retest reliability of the MCS increased the SEM compared to the PCS. An advantage of using the component summary scores rather than the individual scales of the SF-36 is to reduce the standard

deviations and increase the reliability relative to the individual scales. (33) The 95% confidence intervals (CI) of the SEM of individual scales are consistently reported to exceed the standard deviation of these scales. (26,33) That the 95% CI of the SEM of the summary measures is less than one standard deviation unit is consistent with previous literature on other chronic illnesses and population norms. (33) It is also consistent with the view that the component measures increase the certainty around individual scores, facilitating their use in clinical practice. The increased reliability with respect to change also provides the summaries with a power advantage relative to the eight scales for sample sizes needed to detect differences in research settings. (33) Although relative validities of the summary measures compared to each of the eight scales in discriminating between patients were not calculated, previous reports show the MCS has consistently performed as well or better than the best scale in mental health tests, suggesting no trade-off in using the summary scale. (33) With the PCS, reports show the single measure of physical health appears to have an empirical validity of greater than 80% of that achieved by the best physical health test (ie Physical Functioning) in discriminating between subjects of different severity with chronic illnesses. (33) However, the power advantages of the PCS is particularly marked relative to those scales with large standard deviations, such as Physical Role Limitations. The use of scales versus summaries in reporting results is thus influenced by the purposes of the study. For studies which are looking to more confidently assess whether change over time has occurred in physical function, and perhaps have other means of specifying precisely in what areas that may have occurred, such as by physiological measures (eg FEV_1 or exercise tests), then the PCS will have an advantage. Given that in any questionnaire a change score can be achieved in countless ways, it can be argued that an instrument that is accurately assessing whether a real change has taken place or not is of most use, as sorting out how and what has changed requires more specific questioning at an individual level in order to make a meaningful assessment. In this sense, the summaries have the potential to offer complementary information to clinical assessment, in determining whether changes that have occurred are of importance to the patient's assessment of their quality of life.

In assessing asthma health status comparison can be made between the disease-specific and generic health status measures. When considering responsiveness to change, this relates to the reliability of the instruments on repeated testing. The 95 % CI of the SEM of the TOTAL MAQLQ-M score is less than 0.6 of one standard deviation. The 95% CI of the SEM for the PCS is 0.65, and for the MCS is 0.8 standard deviation units. Hence at an individual level one would expect to be more confident about changes in the disease-specific measure than the SF-36 component summaries. The responsiveness to change of either instrument in measuring the minimal clinically important change over time is described in Chapter 6, 'Measuring the clinically important difference in asthma quality of life'. Unless there is a sufficiently greater increase in the variation of the MAQLQ-M scores with time compared to the summary scores, then the MAQLQ-M will be a more powerful test of treatment effects or changes in status (47). The results in Chapter 6," Interpretation of changes in health-related quality of life scores', show the MAQLQ-M to be a more powerful instrument. However, the capability that the SF-36 provides of being able to compare across diseases and with normative scores in the population, remains useful. This is particularly so if larger sample sizes are available for study as the small power advantages the MAQLQ-M has will be of lesser importance in these instances.

The factor analysis showed that the MAQLQ-M could be meaningfully scored as a total or overall score of quality of life in asthma. Sixteen of the 22 items showed correlations of greater 0.30, and all but 2 had loadings greater than 0.25, on one factor, which explained nearly 60% of the common variance. The eigenvalue for this factor was much bigger than the second eigenvalue, and this could be interpreted to confirm the uni-dimensionality of the scale (17). The internal consistency values were high to very high in all domains. For the overall scale and each of the separate domains the values of Cronbach's alpha were higher than those reported for the original instrument (13), as was hypothesised to be the effect of the increase in response points for items (16-18). The finding of a very high Cronbach's alpha coefficient for

the overall scale provides further strong evidence that the questionnaire samples from a single domain of asthma quality of life. The demonstration of the validity of scoring the MAQLQ-M as a single TOTAL score has the advantage of making it possible to reduce the number of statistical comparisons and thereby the role of chance in testing hypotheses about health outcomes (33,48). However, useful information can be gained by examining domain sub-scale scores (7,13,49). The nature of different interventions, eg drugs on breathlessness, cognitive interventions on mood, will affect which sub-scales are most sensitive to changes due to the treatment (49). The presence of factors corresponding to the BREATHLESSNESS and MOOD sub-scales from the original study by Marks et al, were confirmed (13). Marks and colleagues described two other factors with descriptive labels of SOCIAL (7 items) and CONCERNS (7 items), with 3 of the items shared between the two domains. Examination of the original components analysis shows that all of these items had correlations >0.36 on a single factor (13). The results of the present study analysis showed strong loadings on only one factor of all items in the SOCIAL/CONCERNS sub-scales, which explained 6.1% of the variance. It is possible the modification of the response scale has altered the psychometric properties of the AQLQ-M in this way, or that differences between sample populations is sufficient to explain these differences. It could be argued that with the replication of the BREATHLESSNESS and MOOD factor structures, the strong unitary factor of asthma quality of life, and the previously demonstrated close relation between the items that make up the SOCIAL and CONCERNS sub-scales, that these are minor differences. Perpina et al reported that the 4 factors from the original measure adjusted well to one unitary factor which explained 62.5% of the total variance (14). While the questionnaire has been used in studies subsequently to the original paper, no further description of its psychometric properties has as yet been published (41,42). Thus the factor structure of the original instrument may not be replicated across different populations or administration situations. The items from the SOCIAL and CONCERNS sub-scales are not "causal" indicators in the sense used by Fayers and Hand (50). These variables are not symptom measures or treatment effects/side-effects, and are mostly concerned with attitudes towards asthma and the limitations

asthma places on individuals. Hence one would not expect their psychometric properties to alter in the way a symptom or side-effect item will alter depending on the different drug used in a clinical trial (50). The duplication of items in both sub-scales contributed to their high correlation (r= .93). It can be argued that the grouping of items into separate SOCIAL and CONCERNS sub-scales is most useful as an aid to interpreting the impact of asthma various aspects of a person's life, rather than strict psychometric properties of the scale.

The expansion of the MAQLQ-M to 22 items by separating indicator activities combined in the original AQLQ-M into different items did not alter the factor analysis noticeably. As seen my Marks et al, these items had similar factor scores, and these items remained closely related to other items in the Breathlessness sub-scale. The question of whether separating these items provides any advantage in terms of measuring HRQL in those with greater asthma-related disability is examined in Chapter 7, where item-response theory scoring models are used to position items along the scale of HRQL.

Moderate associations were found between the HRQL instruments and reference measures of disease status. The strength of the association was generally greater for symptom measures than for lung function or reported medication use. These are findings in line with those found previously in asthma for other disease-targeted tools and for the SF-36 (3,4,13,43,51). The absence of floor and ceiling effects despite substantial proportions reporting either no symptoms or frequent symptoms in many categories suggests these tools are useful in discriminating between different levels of health at the extremes of quality of life. In multivariate models FEV_1 was not a significant predictive variable, as exercise limitations accounted for nearly all of the effect of spirometry on HRQL scores. A similar effect has also been noted for the St. George's Respiratory Questionnaire (SGRQ) (4). Reported daily inhaled corticosteroid (ICS) dose was a significant independent predictor of HRQL scores, with higher doses being associated with lower perceived quality of life. This would suggest that greater impairment is not due to any large extent to gross undertreatment of asthma. Although subject to the

inaccuracies of self-report of medication use (52), one interpretation of this is that treatment is being appropriately directed at those in need. Given also the significant correlation between FEV_1 and daily ICS dose, it would suggest that quality of life will not be automatically improved by simply increasing prescription of preventive medication. This is particularly so when the lack of proven efficacy of increasing doses of ICS at the top end of the dose-response curve is considered (53). Two further issues are also involved. Some 15-20% of people with asthma are poor perceivers of bronchoconstriction (54). The effect of treatment on the perception of airway calibre is unclear (55). It is also clear that both physiological and psychological factors play a role in the overall ability of an individual with asthma to perceive changes in airway function (55-57). Individual response to symptoms influences medical decisions and treatment intensity (58). Negative emotions have also been observed to heavily influence the subjective expression of asthma (59). Perception of the need for treatment is also separate from perception of symptoms (60). Hence, the relationship between symptoms and treatment is a complex interplay of physiological, emotional and social factors. A further dimension is added by linking between these variables and disease handicap and perceived quality of life. Specific studies that include physiological measures such as perception of bronchoconstriction and airway inflammation along with subjective factors are needed. Examining this inter-relationship will require specific studies that investigate, in combination, perception of bronchoconstriction, airway inflammation, symptoms, lung function, quality of life, treatment and emotional factors such as coping behaviour.

The strongest correlate of the subjective variables of asthma status with HRQL was the self-rating of severity. Marks et al have demonstrated that asthma subjects use a wide range of descriptive terms to indicate the sensation of respiratory discomfort during a bronchial challenge test (61). Different individuals use different combinations of symptoms to describe their asthma, which may vary according to a number of circumstances (55). For these reasons, the more global severity rating may catch these perceptions, along with the impact the condition has on the person, and possibly even

feelings related to the future and how the individual feels their asthma should be progressing. A global rating has been found to be the strongest correlate of disease measures with the Juniper AQLQ (3). The issue of impaired perception of airway obstruction and the effect this may have on an individual's estimation of their asthma severity and quality of life cannot be estimated from the current study. It is a relationship that has not been extensively explored in the research literature as yet, but could offer interesting insights into the how physiology influences handicap.

Comparison between the SF-36 and the MAQLQ-M showed that, as anticipated, the constructs measured by the scales related to physical health impairment, ie BREATHLESSNESS (MAQLQ-M) and Physical Function (SF-36) were strongly associated. Similarly the mental health measures of MOOD (MAQLQ-M) and Mental Health (SF-36) were closely correlated. Not surprisingly, the Pain scale of the SF-36 was only weakly related to the MAQLQ-M. Interestingly, the emotional role limitations of the SF-36, dealing with problems with work and daily activities due to emotional problems, showed only weak correlations with any scales of the MAQLQ-M. This suggests this construct of mental health does not have a similar construct in the MAQLQ-M. This may reflect the more specific disease focus of the MAQLQ-M, where the impact of the illness on emotional condition and the limitations it imposes are measured, rather than the effect of emotional upset on role functioning. Alternatively, it may be due to the narrow focus and weak scaling of this scale of the SF-36 failing to capture a sufficient range of impairment in this area (62).

Correlations between changes in the MAQLQ-M and reference measures of disease status were moderate. Subjective ratings again were more strongly associated with HRQL changes than were the lung function changes. Values were higher than those reported by Marks et al in their original paper on the validity of the questionnaire using the 5-point Likert response scale (11). The findings are consistent with those found for the Juniper AQLQ and the St. George Respiratory Questionnaire (SGRQ) (4,6,7). The correlations are higher than those reported for the Living with Asthma Questionnaire (6).

Whether the stronger associations with clinical measures seen here compared with the original survey reflects differences in sampling or the change from a 5-point response scale to 7-point scale cannot be determined from the data. However, the results indicate that the longitudinal construct validity of the modified questionnaire is at least as good, if not superior to, the original instrument. It should be noted that the values for the correlations and regression coefficients between change in the MAQLQ-M and reference measures were comparable to the values obtained in the cross-sectional data. This suggests that the MAQLQ-M is as sensitive to changes in health status as it is in discriminating between patients. This is comparable with the Juniper AQLQ which was designed to be highly sensitive to changes in clinical trials, and shows stronger associations with disease measures for change than in cross-sectional comparisons (3). This is somewhat unusual for health status instruments, as cross-sectional discriminative ability is commonly greater than longitudinal sensitivity for both disease-specific and generic quality of life surveys (4,6,11,26). The study confirms that the MAQLQ-M is equally valid as a measure of change in HRQL or at a single point in time. Direct comparison in a single population with the Juniper AQLQ is necessary to establish which measure is a more responsiveness instrument for assessing change. That the MAQLQ-M is sensitive to change in all domain sub-scales without the use of 'personalised' items or 'informed administration' is encouraging for ease of clinical use. Both of those properties of the Juniper instrument increase its complexity of administration as a tool for use by non-experts in routine clinical situations, and also limit its use for comparison between different populations. This finding is also consistent with those of Ware et al who found that the increased signal-to-noise ratio caused by personalising the activities scale of the Juniper AQLQ made it less responsive than the AQLQ-M (10).

The data emphasises that clinical measures are limited in closely predicting the day-to-day functioning of patients. It could be argued that regular peak flow monitoring is a better measure of asthma status over time than a point measure of FEV_1 or subjective symptom reporting. However, peak flows capture only single instances in time over a 24-hour period, impose a burden

of measurement on patients, and have not been shown to reliably improve patient outcomes such as hospitalisation rates when compared to symptoms as part of asthma action plans (63-65). Similarly, bronchial hyper-responsiveness lacks sensitivity and specificity for the expression of asthma (66,67). The question as to whether knowledge of the association between these other measures and changes in the HRQL tools improves both our understanding of asthma-related quality of life and of the validity of the measurement tools, remains unclear. Given that the wide variation in the perception of airway narrowing seen in asthma patients (54), and the heterogeneity of patients in terms of circumstances and temperament, a moderate correlation between HRQL and physiological measures is all that should be expected (7). The implication is that quality of life measures add complementary information to conventional clinical outcomes. The following chapter, 'Predicting HRQL status', discusses how the use of a limited number of questions can measure what patients value with regard to their asthma, along with psychosocial distress and conventional clinical status to enhance clinical assessment.

The usefulness of valid generic health surveys such as the SF-36 is that they allow comparisons between different study samples, other illnesses, and with the general population. The data from the SA Omnibus Survey provides further evidence for the validity of the SF-36 as a tool for measurement of HRQL at the group or population level. In the randomised community sample of people with asthma, the SF-36 was sensitive in discriminating between functional deficits according to frequency of nocturnal and morning asthmatic symptoms. Similar to previous reports, patients with severe asthma had mean SF-36 scores significantly lower than population norms. (44,45) However, while lower scores were more pronounced in areas of physical capacity, unlike other reports reduced scores were seen across all dimensions of the SF-36. (68) As the Omnibus Survey was conducted in the Australian spring it may be that the effects of seasonal asthma were being experienced at this time, or that asthma was severe, and that the scores reflect this impact over the previous month. Greater limitations for most dimensions of the SF-36 were associated with symptoms occurring monthly

or less often, compared with seasonal symptoms only. Those with asthma who indicated never having nocturnal or morning symptoms had a SF-36 profile very similar to the general population. Most people reported relatively mild impairment of HRQL due to asthma. As previous studies using the SF-36 in community samples have reported results for 'chronic lung disease' and have not separated asthma from chronic obstructive pulmonary disease or other chronic respiratory disease it is difficult to make direct comparisons with other populations. (69) Previous reports of the AQLQ-M in community samples have indicated most people perceive fairly mild impairment in quality of life due to asthma. (41,42) The present study population reported significantly worse quality of life than the community asthma sample, reflecting selection through recruitment from hospital clinics.

The low general health perception scores even in those who never experience symptoms suggests the label of asthma may create doubts about the self and of self value. Becker et al have noted the importance to Western cultural ideals of the notion that individuals can control their environment and that taking responsibility for one's health is highly valued. (70) The risk is that the individual alone becomes responsible when things go wrong, and become vulnerable to being stigmatised and blamed for being the victim of asthma. This perception may be of some long-standing in individuals with asthma, dating back to childhood. (71) It is possible the effect of being labelled with a diagnosis of asthma, or the need to take medication to control symptoms may cause poorer health perceptions. A similar phenomenon has been described in people diagnosed with hypertension, with increases in work absenteeism, and more depressive symptoms and lower self-reported health status following a diagnosis of hypertension that could not be explained by greater utilisation of health services or co-morbidity. (72,73) Whether there is an underlying physiological or biochemical change causing diminished health without continued respiratory symptoms is yet to be determined. It has been suggested that certain biomedical premises and behaviours stigmatise patients with asthma, and it is possible that these are contributing factors to the low general health perceptions seen here. (70) Combined with the association of HRQL with negative coping styles described in Chapter 5,

'Predicting health-related quality of life status in asthma', this suggests this is an important area in which to direct interventions in order to alter cognitive appraisals or restructure beliefs to enhance HRQL for asthma patients.

Inability to work, or to perform usual activities, are important social and economic consequences of illness. The total annual cost to the Australian community of asthma related absenteeism was estimated in 1991 to be in the range of $200 to $234 million in 1991. (74) Ware et al, using data from the Medical Outcomes Study, showed that the percentage of those eligible to work but unable to do so due to poor health varied according to SF-36 Physical component summary (PCS) scores. (33) In the Omnibus study, the SF-36 discriminated between those in the community who had lost activity days due to asthma and those who had not over the past year. This provides further evidence of the discriminative validity and usefulness of the SF-36 in population surveys of asthma.

The identification of areas of altered quality of life that are possibly not directly related to respiratory limitations is an area where general health measures may have an advantage over disease-targeted asthma quality of life questionnaires in directing management and further research. Evidence from clinical drug trials has been conflicting regarding the sensitivity to change in these domains of the SF-36. (45,75) The data from this study demonstrates the longitudinal validity of the SF-36 as a measure of change in patients with asthma.

Some comment on the Omnibus Study methodology is warranted. The self-reported measure of asthma that has been confirmed by a doctor is useful as it is a simple tool which is able to be compared across years because it is an inexpensive measure, and it enables targeted morbidity estimates. (36) It has been used in a number of previously reported epidemiological studies. (76,77) Self-report of physician diagnosed asthma has been reported to have high specificity (99%) and to be reliable for asthma regardless of the mode of validation, although sensitivity is lower. (78-81) A recent review called for the use in surveys of items about asthma with high specificity, especially citing

"physician-diagnosed asthma" as a question with such properties. (76) Objective data on lung function or airway hyperresponsiveness was not available for the Omnibus population. Although BHR would provide an objective measure for future comparison, reports have shown it lacks sensitivity and/or specificity for asthma. (81-83) Surveys that use the frequency of symptoms to define asthma also do not take into account the potential confounding effect of management that aims to reduce symptoms. (77,84) If, however, asthma is being under-diagnosed in the community then the study would tend to under-report morbidity. Alternatively, some authors have argued for using simple respiratory symptoms as end points, in order to avoid diagnostic bias and misclassification. (76,78) All community surveys will have problems with potential misclassification of subjects. (76) However, this survey, using a very high quality sampling methodology weighted to the South Australian population, achieved results that are able to be generalised to the whole population of adults, and differences in the indicators are likely to reflect true differences in the population, rather than being artefacts of methodological problems.

Conclusion

The greater construct validity of the disease-targeted tool (modified AQLQ-M), is to some degree balanced by the comparative ability of the generic instrument (SF-36). The use of generic or disease-targeted tools will thus be largely determined from the objectives of the research or clinical question that is posed. The proportion of any study sample that is elderly will also affect this decision. Disability and handicap are composite measures that are not disease specific and can be influenced by co-morbidities, which tend to increase with age. (85) Therefore, there is a place for both generic and disease-targeted measures to gain a clear picture of patient outcomes. (10)

The information gained from the SF-36 in allowing comparisons with population norms and with other conditions can be valuable. Hence the use of generic and / or disease-targeted instruments will largely depend on the questions posed and the settings of their use.

Table 1: Health-related quality of life scores.

	Mean	Std. Dev.	25th percentile	75th percentile
***Total* MAQLQ-M**				
Baseline (n=293)	4.2	1.2	3.2	5.4
3 months	4.4	1.2	3.1	5.6
6 months	4.4	1.3	3.5	5.4
9 months	4.5	1.2	3.6	5.7
12 months (n=232)	4.5	1.3	3.4	5.8
PCS				
Baseline (n=293)	39.1	11.0	31.2	47.4
3 months	39.8	12.8	29.1	51.0
6 months	41.8	12.7	31.8	52.8
12 months (n=232)	40.3	12.1	29.9	51.2
MCS				
Baseline (n=293)	39.6	12.2	31.0	49.7
3 months	40.7	10.9	33.6	49.4
6 months	40.6	12.1	31.3	50.2
12 months (n=232)	40.5	12.2	33.0	49.2

Table 2. Comparison at baseline for those with and without 12 month follow-up for the SF-36 and *Total* MAQLQ-M.

	Mean	Std. Dev.	Minimum	Maximum
***Total* MAQLQ-M**				
With 12 (n=232)	4.4	1.4	1.7	6.8
Without 12 (n=232)	4.1	1.4	1.0	6.7
PCS				
With 12 (n=232)	38.2	11.1	12.7	60.7
Without 12 (n=232)	39.5	11.0	14.7	59.8
MCS				
With 12 (n=232)	40.9	12.3	11.3	61.9
Without 12 (n=232)	39.0	12.2	5.5	66.9

Table 3: Cross-sectional and Longitudinal Internal Consistency & Reliability

	α	Ave. inter-item correlation	SEM[+]	95% CI[**]	Reliability[#] (Test-retest)	SEM	95% CI[*]
Total	.97	.58	.20	.40	.93	.31	.62
Breathless	.95	.71	.27	.54	.91	.36	.72
Mood	.90	.62	.38	.76	.88	.41	.82
Social	.96	.74	.28	.56	.93	.38	.75
Concerns	.92	.63	.37	.74	.91	.40	.79
PCS	.92	.61	3.1	6.2	.90	3.5	7.0
MCS	.89	.58	4.0	8.0	.86	4.6	9.2

[#]Intra-class correlation coefficient [*]95% CI equals 2 SEM (standard error of measurement)

Table 4: MAQLQ-M: Principal components analysis with varimax rotation.

		Factor Loadings			
	Item-total correlation	Factor 1	Factor 2	Factor 3	Communality estimate
SOB [B]	.77	.81		.31	.77
Wheeze [B]	.70	.78			.73
Tightness [B]	.70	.75			.72
Walking [B]	.80	.75		.45	.80
Light h/w [B]	.80	.75		.44	.81
Uphills [B]	.75	.71		.48	.76
Heavy h/w [B]	.80	.69		.51	.80
Tired [M]	.72	.51	.48	.34	.58
Sleep [M]	.64	.42	.56		.50
Sad [M]	.61		.87		.71
Anxious [M]	.61		.84		.69
Frustrated [M/C]	.72		.70	.40	.67
Achieve [S/C]	.84	.37	.32	.73	.78
Soc. Life [S]	.83	.38		.75	.78
Places [S]	.75	.30		.75	.67
Get help[S/C]	.76			.73	.67
Sport [S]	.76	.36		.75	.75
Restricted [S]	.79	.40		.75	.81
Control me [S/C]	.83	.36		.78	.77
Future [C]	.78		.33	.75	.78
Short life [C]	.72		.36	.71	.71
Sprays [C]	.56	.33		.52	.39
Eigenvalue		13.1	1.5	1.4	
Variance explained		59.5%	7.0%	6.1%	

Note: Subscales of the MAQLQ-M- [B] = *Breathlessness,* [M] = *Mood,* [S] = *Social,* [C] = *Concerns*

Table 5: Pearson product moment correlations between MAQLQ-M and disease reference measures.

	Total	*Breathless.*	*Mood*	*Social*	*Concerns*
Symptoms-					
Night symptoms	.35^{+}	.38^{+}	.22$^{\#}$	.30**	.34**
Morning symptoms	.36^{+}	.40	.20$^{\#}$	.29*	.36^{+}
Exercise limitations	.42	.45	.36^{+}	.32**	.36^{+}
Attack frequency	.38^{+}	.38^{+}	.25*	.34**	.34**
Total symptoms	.53	.56	.37^{+}	.43	.48
Self-rating	.48	.47	.40	.41	.47
General change in asthma*	.56	.54	.45	.50	.53
Medication- Reliever use**	-.37^{+}	-.33**	-.19$^{\#}$	-.42	-.42
ICS (mcg/day)	-.29*	-.24*	-.25*	-.31**	-.32**
FEV_1 (% predicted)	.30**	.32**	.22$^{\#}$	.34**	.24*
Global Health Rating	.46	.48	.38^{+}	.40	.44

Note: #p<0.05; *p<0.01; **p<0.001; +p<0.0001; all others p<0.00001

Table 6. Cross-sectional Construct validity of the MAQLQ-M

Linear regression for MAQLQ-M and reference measures of disease activity.

BREATHLESSNESS

	B	se B	Beta	r^2	p
Symptoms					
Morning	.28	.07	.31	.10	.000048
Exercise	.51	.08	.45	.20	.000000
Attacks	.43	.08	.40	.16	.000000
Total	1.33	.18	.49	.24	.000000
Self-rating of severity	.29	.05	.45	.20	.000000
General change in asthma**	.22	.04	.49	.24	.000000
Medication					
Reliever use++	-.18	.06	-.22	-.05	.0043
ICS dosage##	-274	76.5	-.30	-.09	.0046
FEV_1 (% predicted)	.27	.09	.30	.10	.00004
Social Impact					
Hospital admissions	.25	.06	.31	.10	.00005
Emergency attendances	.28	.11	.20	.04	.01
Activity days affected	.25	.06	.35	.12	.00005

**"Do you feel your asthma is generally getting better / worse / the same?

++Frequency of reliever use scored 1 to 4 (86)

##ICS dosage in mcg/day

Table 6 (Continued)

Cross-sectional Construct validity of the MAQLQ-M

Linear regression for MAQLQ-M and reference measures of disease activity.

MOOD

	B	se B	Beta	r^2	p
Symptoms					
Morning	.16	.08	.15	.02	.048
Exercise	.43	.10	.32	.11	.00002
Attacks	.31	.10	.24	.06	.0016
Total	.99	.23	.32	.10	.00003
Self-rating of severity	.28	.06	.32	.14	.000001
General change in asthma**	.18	.04	.36	.13	.000004
Medication					
Reliever use++	-.18	.07	-.20	-.01	.003
ICS dosage##	-287	86	-.28	-.08	.00115
FEV_1 (% predicted)	.29	.10	.20	.04	.007
Social Impact					
Hospital admissions	.28	.07	.31	.09	.00006
Emergency attendances	.41	.12	.25	.06	.0013
Activity days affected	16.7	5.8	.25	.06	.0045

**"Do you feel your asthma is generally getting better / worse / the same?

++Frequency of reliever use scored 1 to 4 (86)

##ICS dosage in mcg/day

Table 6 (Continued)

Cross-sectional Construct validity of the MAQLQ-M

Linear regression for MAQLQ-M and reference measures of disease activity.

SOCIAL

	B	se B	Beta	r^2	p
Symptoms					
Morning	.14	.06	.17	.03	.03
Exercise	.37	.07	.37	.13	.000001
Attacks	.34	.07	.36	.13	.000002
Total	.91	.17	.38	.15	.000000
Self-rating of severity	.27	.04	.47	.22	.000000
General change in asthma**	.16	.03	.40	.16	.000000
Medication					
Reliever use++	-.18	.05	-.25	-.06	.0011
ICS dosage##	-304	66	-.37	-.14	.00001
FEV_1 (% predicted)	.36	.08	.35	.12	.00001
Social Impact					
Hospital admissions	..23	.05	.33	.11	.000017
Emergency attendances	.36	.09	.29	.09	.00015
Activity days affected	18	4.4	.33	.11	.00011

**"Do you feel your asthma is generally getting better / worse / the same?

++Frequency of reliever use scored 1 to 4 (86)

##ICS dosage in mcg/day

Table 6 (Continued)

Cross-sectional Construct validity of the MAQLQ-M

Linear regression for MAQLQ-M and reference measures of disease activity.

CONCERNS

	B	se B	Beta	r^2	p
Symptoms					
Morning	.22	.07	.25	.06	.0013
Exercise	.43	.08	.39	.15	.000000
Attacks	.39	.08	.37	.13	.000001
Total	1.15	.19	.43	.19	.000000
Self-rating of severity	.32	.04	.50	.25	.000000
General change in asthma**	.18	.03	.41	.17	.000000
Medication					
Reliever use++	-.24	.06	-.29	-.08	.00016
ICS dosage##	-329	73	-.36	-.13	.00001
FEV_1 (% predicted)	.30	.09	.24	.06	.001
Social Impact					
Hospital admissions	.27	.06	.34	.12	.00001
Emergency attendances	.46	.10	.33	.11	.000016
Activity days affected	20	4.9	.35	.12	.00005

**"Do you feel your asthma is generally getting better / worse / the same?

++Frequency of reliever use scored 1 to 4 (86)

##ICS dosage in mcg/day

Table 6 (Continued)

Cross-sectional Construct validity of the MAQLQ-M

Linear regression for MAQLQ-M and reference measures of disease activity.

TOTAL

	B	se B	Beta	r^2	p
Symptoms					
Morning	.24	.07	.24	.06	.00165
Exercise	.52	.09	.42	.18	.00000
Attacks	.44	.08	.38	.14	.000001
Total	1.3	.20	.45	.20	.000000
Self-rating of severity	.34	.05	.48	.23	.000000
General change in asthma**	.22	.03	.46	.21	.000000
Medication					
Reliever use++	-.21	.07	-.24	-.06	.0019
ICS dosage##	-349	81	-.35	-.12	.00003
FEV_1 (% predicted)	.39	.10	.31	.10	.00006
Social Impact					
Hospital admissions	.30	.06	.35	.12	.000005
Emergency attendances	.43	.11	.28	.08	.00022
Activity days affected	23	5.4	.36	.13	.000035

**"Do you feel your asthma is generally getting better / worse / the same?

++Frequency of reliever use scored 1 to 4 (86)

##ICS dosage in mcg/day

Table 7. Cross-sectional Construct validity of the SF-36.

Linear regression for PCS & MCS and reference measures of disease activity.

PCS

	B	se B	Beta	r^2	p
Total Symptoms	.03	.04	.44	.20	.000001
Self-rating of severity	.31	.20	.47	.22	.000000
Medication					
Reliever use[++]	.14	.09	.20	.04	.006
ICS dosage[##]	-.0001	-.0001	.22	.05	.001
FEV_1					
(% predicted)	.06	.02	.28	.08	.0005
Social Impact					
Hospital admissions	.27	.06	.30	.09	.00004
Emergency attendances	.49	.10	.22	.05	.005
Activity days affected	19	4	.33	.11	.00001

MCS

	B	se B	Beta	r^2	p
Total Symptoms	.85	.20	.30	.10	.00009
Self-rating of severity	.31	.06	.36	.14	.000001
Medication					
Reliever use[++]	-.18	.07	-.20	-.04	.003
ICS dosage[##]	-260	86	-.25	-.07	.003
FEV_1					
(% predicted)	.20	.11	.22	.05	.004
Social Impact					
Hospital admissions	.19	.07	.28	.08	.0006
Emergency attendances	.38	.15	.25	.06	.0013
Activity days affected	19	5	.20	.04	.01

**"Do you feel your asthma is generally getting better / worse / the same?

++Frequency of reliever use scored 1 to 4 (86) [##]ICS dosage in mcg/day

Table 8: Multiple linear regressions between MAQLQ-M scales, & SF-36 Component Summaries, as the dependent variables, and disease measures.

	Total		*Breathlessness*		*Concerns*		*Social*	
	β (SE)	p	β (SE)	p	β (SE)	p	β (SE)	p
Symptoms	.18 (.11)	.07	.31 (.09)	.000	.15 (.11)	.17	.18 (.10)	.10
Rate severity	.33 (.09)	.000	.24 (.09)	.007	.34 (.09)	.000	.35 (.09)	.000
ICS dose/day	-.20(.07)	.007	-.18(.07)	.015	-.17 (.07)	.019	-.21 (.08)	.008
Reliever usage	.09 (.07)	.24	.10 (.08)	.17	.02 (.08)	.82	.04 (.08)	.61
Exercise limits	.25 (.09)	.008	.23 (.10)	.014	.20 (.09)	.04	.26 (.10)	.009
FEV_1	.07 (.10)	.56	.12 (.08)	.09	.10 (.07)	.20	.03 (.11)	.81
Adjusted r^2	.48		.47		.47		.41	

	Mood		**PCS**		**MCS**	
	β (SE)	p	β (SE)	p	β (SE)	p
Symptoms	.14 (.10)	.19	.07 (.14)	.55	-	-
Rate severity	.28 (.10)	.007	.30 (.09)	.001	.25 (.10)	.009
ICS dose/day	-.19 (.08)	.025	-.18 (.07)	.02	-.16 (.08)	.036
Reliever usage	.18 (.09)	.049	.10 (.07)	.16	.15 (.09)	.068
Exercise limits	.20 (.11)	.07	.22 (.10)	.01	.16 (.11)	.11
FEV_1	.01 (.13)	.93	.09 (.10)	.28	.01 (.16)	.95
Adjusted r^2	.27		.38		.22	

Table 9: Mean MAQLQ-M & SF-36 Component Summary scores by symptom categories

Category (% pop.)	*Total*	*Breathless.*	*Mood*	*Social*	*Concerns*	PCS	MCS
Self-rate severity							
Severe (23)	3.7	3.4	3.6	3.6	3.4	36.2	35.5
Moderate (43)	4.4	4.4	4.4	4.7	4.4	40.1	40.6
Mild (26)	5.3	5.3	5.0	5.5	5.4	47.5	49.0
No problem (9)	5.6	5.2	6.1	5.7	5.5	51.0	51.8
Attack frequency							
Persistent (22)	3.6	3.5	3.8	3.7	3.5	34.5	34.1
> Weekly (17)	4.0	4.0	4.2	4.2	4.0	38.7	39.1
> Monthly (12)	4.5	4.1	4.4	5.0	4.7	41.6	42.6
>3 / year (33)	5.0	5.1	4.6	5.3	5.0	45.4	46.0
<3 / year (14.9)	5.2	5.5	5.0	5.5	5.2	47.8	48.2
Never (1.3)	6.2	5.8	5.4	6.9	6.6	51.7	52.5
Morning sympt.							
Every day (19)	3.9	3.7	3.9	4.3	3.9	36.5	36.9
Most days (19)	4.2	4.1	4.3	4.4	4.2	39.2	39.6
Once week (30)	5.1	5.1	4.8	5.6	5.2	42.1	43.6
Once month (7)	5.4	5.7	5.1	5.2	5.3	47.2	49.6
Never (25)	5.5	5.7	5.2	5.3	5.4	47.4	49.7
Nocturnal sympt.							
Every night (19)	3.9	3.8	3.9	4.3	3.9	36.9	37.3
Most nights (32)	4.0	3.8	4.0	4.2	4.0	37.0	37.5
Once week (26)	4.9	4.8	4.8	5.2	5.0	45.3	46.0
Once month (13)	4.9	4.8	4.8	5.3	5.1	45.4	45.9
Never (10)	5.2	5.2	5.3	5.6	5.2	48.9	49.5
Exercise limits							
Dressing (6)	3.6	3.6	3.7	3.9	3.6	35.2	35.1
Walk on flat (11)	2.9	3.6	3.1	3.1	3.1	33.9	34.2
Hurry on flat (13)	3.9	3.9	4.1	4.0	3.9	38.6	38.4
Uphill/stairs (31)	4.7	4.5	4.5	5.1	4.8	42.6	43.5
Sports (19)	4.7	4.6	4.5	4.9	4.8	42.5	43.2
No limits (20)	5.8	6.0	5.5	6.1	5.7	51.6	50.5
FEV_1 (% pred.)							
<60% (30)	3.4	3.2	3.4	3.5	3.4	33.4	34.6
60-80% (40)	4.4	4.5	4.3	4.4	4.4	43.3	44.5
>80% (30)	4.9	4.9	4.7	4.7	4.8	47.6	49.4

Table 10: Correlations between SF-36 and MAQLQ-M

SF-36	*Total*	*Breathlessness*	*Mood*	*Social*	*Concerns*
PFI	.67	.71	.50	.59	.56
PAIN	.37**	.25*	.36	.35**	.37
GHP	.68	.63	.54	.63	.64
VITL	.73	.58	.66	.69	.64
SOC	.63	.52	.52	.63	.62
ROLE	.44	.36**	.42	.41	.43
MHL	.67	.50	.69	.66	.63
PCS	.71	.69	.55	.66	.61
MCS	.62	.52	.65	.64	.64

Note: *p<0.01; **p<0.0001; all others p<0.00001

Note: PFI: Physical Functioning VITL: Vitality
ROLP: Role Limitations-Physical SOC: Social Functioning
PAIN: Bodily Pain ROLE: Role Limitations-Emotional
GHP: General Health Perceptions MHL: Mental Health
PCS: Physical Component Summary MCS: Mental Component Summary

Table 11: Comparison of SF-36 and MAQLQ-M at baseline.

Linear regression between MAQLQ-M (as the dependent variable) and SF-36

	BREATHLESSNESS			MOOD		
SF-36	Coeff.	SE	R^2	Coeff.	SE	R^2
PFI	.27	.03	.50	.13	.02	.25
PAIN	.09	.03	.06^{+}	.08	.02	.12$^{\#}$
GHP	.26	.03	.39	.14	.02	.28
VITL	.27	.04	.33	.20	.02	.43
SOC	.20	.03	.26	.13	.02	.27
ROLE	.09	.02	.12$^{\#}$	.07	.02	.17
MHL	.23	.04	.25	.21	.02	.47
PCS	.27	.03	.48	.15	.02	.44
MCS	.21	.03	.26	.19	.02	.42

	SOCIAL			CONCERNS			TOTAL		
SF-36	Coeff.	SE	R^2	Coeff.	SE	R^2	Coeff.	SE	R^2
PFI	.31	.04	.34	.22	.03	.31	.82	.09	.44
PAIN	.16	.05	.11*	.14	.03	.13	.40	.11	.12$^{\#}$
GHP	.33	.04	.39	.30	.04	.40	.84	.10	.46
VITL	.42	.05	.48	.30	.04	.40	1.03	.10	.52
SOC	.30	.04	.39	24	.03	.38	.72	.09	.39
ROLE	.14	.03	.16	.12	.02	.18	.35	.08	.18
MHL	.40	.05	.43	.30	.04	.39	.82	.09	.44
PCS	.40	.04	.43	.23	.04	.37	.92	.10	.50
MCS	.35	.04	.40	.30	.04	.40	.70	.09	.38

$^{\#}p< .0003$ *$p< .0005$ $^{+}p= .01$ All other values significant at $p< .0001$.

Note: PFI: Physical Functioning VITL: Vitality
ROLP: Role Limitations-Physical SOC: Social Functioning
PAIN: Bodily Pain ROLE: Role Limitations-Emotional
GHP: General Health Perceptions MHL: Mental Health
PCS: Physical Component Summary MCS: Mental Component Summary

Table 12: Comparison of SF-36 scores between SA population norms (87), Community Asthma sample (SA Health Omnibus Study), and Current Study patients.

(Note: Adjusted for age, gender, and socioeconomic status (35))

SF-36	General population (st. dev)	Asthma-community (st. dev)	Difference* (95% CI)	Asthma-Study patients (st. dev)	Difference** (95% CI)
PFI	86.4	77.8	-8.6	60.3	-17.5
	(21.6)	(22.9)	(-6.3, -11.0)	(27.5)	(-14.0, -20.6)
ROLP	81.3	71.2	-10.1	37.9	-33.3
	(34.9)	(33.8)	(-5.8, -14.4)	(42.7)	(-28.2, -39.9)
PAIN	77.9	71.5	-6.4	69.3	-2.2[#]
	(25.5)	(23.6)	(-3.2, -9.5)	(31.2)	(+1.4, -5.8)
GHP	74.8	61.1	-13.7	41.7	-19.4
	(21.7)	(21.6)	(-11.1, -16.3)	(25.4)	(-16.0, -22.5)
VITL	64.9	58.4	-6.5	41.6	-16.8
	(21.4)	(20.9)	(-3.9, -9.0)	(22.5)	(-13.4, -20.6)
SOC	89.0	81.1	-7.9	61.3	-19.8
	(21.3)	(22.4)	(-5.2, -10.6)	(28.7)	(-15.8, -24.8)
ROLE	88.3	79.3	-9.0	56.4	-22.9
	(28.9)	(33.1)	(-5.3, -12.6)	(44.0)	(-17.3, 27.6)
MHL	79.2	74.4	-4.8	63.0	-11.4
	(17.7)	(18.1)	(-2.6, -7.0)	(22.1)	(-8.2, -14.4)
PCS	50	45.9	4.1	39.1	-6.8
	(10)	(10.8)	(2.2, 6.0)	(11.0)	(-5.5, -8.0)
MCS	50	48.0	2.0	39.6	-8.4
	(10)	(11.7)	(0.8, 3.3)	(12.2)	(-7.0, -9.8)

*Comparison of means: population norms and community asthma sample

**Comparison of means: community asthma sample and Study patients.

All values $p<0.0001$ unless otherwise indicated. [#]$p= .26$

Note: PFI: Physical Functioning; VITL: Vitality; ROLP: Role Limitations-Physical; SOC: Social Functioning; PAIN: Bodily Pain; ROLE: Role Limitations-Emotional; GHP: General Health Perceptions; MHL: Mental Health; PCS: Physical Component Summary; MCS: Mental Component Summary

Table 13. Mean SF-36 scores for asthma subjects according to days lost from work, school or home duties because of asthma.

SF-36 dimension	No days lost	Days lost
Phys. Functioning	79.3	69.3
Role-Physical	75.0	52.1
Bodily pain	74.2	55.3
General Health	64.1	46.9
Vitality	59.3	45.4
Soc. Functioning	83.5	67.1
Role-emotional	80.2	71.5
Mental Health	74.7	68.2

Table 14: Longitudinal construct validity. Change in *Total* MAQLQ-M, &PCS (SF-36), and change in other measures over 3 months. (n=254)

	Total MAQLQ-M		PCS	
	Pearson r	p	Pearson r	p
Δ Total Symptoms*	.46	.000	.33	.008
Δ FEV_1*** (% predicted)	.19	.038	.15	.055
Self-rating of severity	.48	.000	.40	.001
General change in asthma**	.60	.000	.48	.000
Medication- Reliever use++	.28	.01	.20	.046
ICS dosage	.33	.006	.22	.04

Table 15: Longitudinal construct validity. Random-effects regression model for change in Total MAQLQ-M, and changes in references measures of disease activity over 3 months.

(n baseline=293, n at 3 month follow-up = 254)

	Coefficient (95% CI)	p
Δ Total Symptoms*	.19 (.02, .36)	.03
Δ FEV_1*** (% predicted)	.14 (-.04, .70)	.21
Self-rating of severity	.44 (.13, .76)	.01
General change in asthma**	.58 (.18, .99)	.004
Medication- Reliever use++	.30 (-.06, .65)	.10
ICS dosage	.38 (-.05, .80)	.08

*Change in symptom scores. **"Do you feel your asthma is generally getting better / worse / the same?

***Change in FEV_1 ++Frequency of reliever use scored 1 to 4 (86)

Change in ICS dosage in mcg/day of >20% from baseline dose.

Chapter 5

Predicting Health-related Quality of Life status in asthma.

Introduction

Previous studies have indicated strong correlations between psycho-social factors such as coping styles and self-efficacy and health-related quality of life (HRQL) in chronic conditions such as diabetes and rheumatoid arthritis. (1-4) The coping strategies of avoidance and emotional reaction have been reported to be associated with HRQL in elderly (mean age 65 years) COPD patients. (5) Less work has been done in asthma. Kinsman's Denver group developed the concept of psycho-maintenance, focusing particularly on anxiety, panic-fear, and dependency, in explaining asthma patient's attitudes and behaviour. (6-12) This required a complex assessment tool of up to 719 questions and placed little emphasis on socio-demographic influences on behaviour. It was also developed in a hospitalised population at a major national referral centre in the US, which may limit the more general applicability of the measurement tool and the conclusions. Dutch researchers have found that cognitions and coping determined a part of the variance in morbidity, in addition to clinical severity. (13,14) In contrast to the Denver studies, anxiety did not contribute to the explanation of the variance in hospital admissions, nor did psychological variables substantially influence the amount of medicine taken. Most of this work in asthma was done in the 1970's and early 1980's and pre-dates the current approach to asthma management using regular preventive medication. Thus the influence of psycho-social factors on chronic asthma self-management is much less well explored. More recent work has found that patients' panic-fear and irritability were associated with the doctor's decision to prescribe steroids in acute asthma attacks. (15) Weak correlations only have been reported between panic-fear and health care utilisation in an outpatient sample. (16) Short-term follow-up of asthma subjects has suggested psychosocial influences over clinical outcomes. (17) Socio-economic status has been reported to affect

asthma morbidity and mortality. (18-24) Little work has examined the relationship between psychological factors, socio-economic status, and clinical status, on asthma outcomes, particularly quality of life.

It has been asserted that current asthma medications are adequate to control manifestations of the condition in most patients, if used correctly. (25) There have been a range of categories of asthma severity based on symptoms (26). Some asthma guidelines use symptom characteristics before treatment (27), whereas others do not specify the relationship to treatment except to qualify that the use of regular inhaled steroids excludes a grading of mild asthma (25). The interplay of physical status, symptoms, psychological status and perception in an individual asthmatic determines how that individual functions. Disability may be either a direct result of impairment of airway function or as a psychological response to the impairment (28). Rules for assessing the respiratory impairment in asthma have generally relied on individual physiological measures (29), and even then there is some discrepancy between the ranges of lung function (FEV_1) that are used for the severity gradings between different countries (30). Widespread agreement on which criteria should be used for assessing asthma severity is not available. (31) In addition, it can be argued that disease severity and health care utilisation are largely independent issues as optimal management will largely prevent hospitalisation and emergency department use. (31) Hence, there still exists considerable confusion as to how symptoms and impairments are linked with disability and handicap in asthma. (28) Quality of life instruments have a pragmatic value in assessing patient outcomes that recognise the importance of separating the essential characteristics from the ideal in examining the impact of a condition on a person's life. (32,33) To understand the factors that can predict HRQL and predict important changes in HRQL in asthma would be potentially useful in developing interventions that would take advantage of available treatment to maximise patient outcomes.

This study sought to examine the influence of psychological, social, economic and clinical factors on quality of life, both cross-sectionally and longitudinally

on a population of asthma patients recruited from two hospitals. It was hypothesised that clinical status and psychosocial factors would show equally strong associations with HRQL. Specifically, it was anticipated that self-efficacy, social support, and active coping would show independently positive effects on HRQL, and that avoidance coping and financial difficulties would impact negatively on HRQL. Secondly, it was hypothesised that over a relatively short time period of 3-months, changes in clinical features would be more closely associated with changes in HRQL than psychosocial factors.

Methods

Survey methodology is described in Chapter 3, "Methods". Questionnaires included the Modified Asthma Quality of Life Questionnaire (MAQLQ-M) and the MOS Short-Form 36 (SF-36) Health Survey (34-36), along with the battery of measures for psycho-social, clinical and demographic variables. These were administered at 3 monthly intervals. The psychosocial measures are summarised in Table 1. The HRQL and clinical measures are shown in the appendix, pages 355,359-362 and pages 349-354.

Random effects GLS regression models were developed to examine the effect of time, differences between hospitals age and gender on QOL scores. Haussman specification test was used to test the appropriateness of each of the random effects models. Random-effects models are appropriate for analysing longitudinal data when the data are continuous, normally (or near normally) distributed, and have numbers of missing observations. (37) The models include both overall effects, which are generally fixed effects, and within-subject effects, that are often considered to be random-effects. (37) These models assume that correlation among repeated responses arises because regression coefficients vary across individuals as a result of unobserved factors that are common to all of the responses for a given person but which, in turn, vary across people. (37,38) These models are useful when inferences are to be made about individuals. (38) Univariate analyses were performed for the effect of each of the psychosocial variables

and HRQL scores. Those variables significant at conventional levels were then examined in multivariate analyses to develop a final model for QOL. Clinical variables were then added to the model to assess the effect and interaction of the psychosocial and clinical variables on HRQL. To determine which variables were associated with changes in HRQL, correlations between change scores, psychosocial variables and disease measures were performed. A multivariate model was developed controlling for baseline HRQL scores. To gain a better understanding of the effect of the psychosocial variables postulated to influence changes in asthma HRQL, the avoidance and active coping scales and the self-efficacy scale were broken into thirds, and the changes in all sub-scales of the MAQLQ-M over 12 months were compared for the top and bottom thirds of the coping and self-efficacy distributions. A similar estimation was made for the dichotomous variables of financial difficulties over 12 months and cost concerns delaying asthma care.

Regression models were also developed for the dependent variables of self-reported adherence to treatment recommendations, and for self-reported frequency of bronchodilator usage.

Results

Responses were obtained from 293 subjects at baseline and from 232 persons at the 12-month follow-up, a 79% retention rate. There was a predominance of females with 33% of subjects being male. Mean age of the population was 42.3 years , with a median age of 41 years, and a range of 15 to 85 years. Fifty-five percent were recruited from The Queen Elizabeth Hospital, the remainder from the Lyell McEwin Health Service. Comparison of the scores at baseline for those with and without 12-month follow-up is showed no statistically significant differences in scores between these two groups (p= .58), and standard deviations and score ranges suggested similar distributions of scores. There were no statistically significant differences in the two groups with and without 12-month follow-up when compared for age, gender, baseline symptoms, or household income.

The effects of time on follow-up scores and comparisons between hospitals over time are shown in Table 2. For the unadjusted scores, there was a small but statistically significant improvement in SF-36 PCS scores over time. The size of this change can be judged when one considers that the standard deviation of the PCS scores was 11.0 and the coefficient of the random effects regression was 0.189, indicating an improvement of less than two-hundredths of one standard deviation. There was a difference in PCS scores over time between hospitals due to a small but significant improvement at TQEH. The MCS scores showed no changes over time, nor any differences between hospitals. The TOTAL Asthma Quality of Life Scores also improved significantly over time, and the magnitude of this change was of similar proportions to that of the PCS. A trend towards improvement at TQEH was seen, but this was not significant at conventional levels.

The effects of age, gender and survey on the QOL measures are shown in Tables 3 and 4. Compared with the reference group of subjects aged 15-34 years, there was a significant negative effect of age on scores on the PCS and the TOTAL MAQLQ-M. The magnitude of this reduction in scores was around half of one standard deviation unit for both measures in the 45-54 years age group, increasing to around one standard deviation for those aged over 65 years. There was no significant effect of age on the Mental Health component summary. When the scores are adjusted for age, the PCS and the MAQLQ-M showed a small but significant improvement at the 6 and 12-month follow-up surveys compared with baseline. The size of this improvement was greater for the PCS than for the TOTAL MAQLQ-M scores, in standard deviation terms. Comparison between the two hospitals controlled for age also showed a small but significant difference, with the LMHS patients scoring lower than TQEH patients in the PCS and TOTAL MAQLQ-M. No difference was seen between hospitals for the MCS when controlled for age.

No effect of gender was seen on the SF-36 or TOTAL MAQLQ-M scales. Examination of the effect of gender on each of the MAQLQ-M sub-scales showed a significant effect on the SOCIAL and CONCERNS scores, with females scoring higher than males. There were small but significant improvements with time for all sub-scales except the SOCIAL scale, when controlled for age. The score change was less than 0.2 for each of the scales. Age has a consistently negative effect for age groups greater than 50 years compared with the youngest subjects (15-19 years), for all sub-scales except MOOD. MOOD scores were not affected by age at all.

The internal consistency and average inter-item correlations of the various scales used in the study are shown in Table 1. These show adequate values for most scales, with the possible exceptions of the health as a value and socially desirable responses scales. (39) Univariate analyses of the effect of a number of psychosocial variables on quality of life when controlled for age are shown in Table 5. No significant effects on any HRQL measure were seen for denial, health as a value, or socially desirable responses. There was a trend for higher self-management autonomy preferences to increase MCS scores, and for more social support to increase PCS scores but these did not reach conventionally significant levels. Higher Satisfaction with illness, or positive evaluations of asthma, had a large positive effect on MCS. The coping style of avoidance had a major effect on all HRQL measures, with less avoidance increasing scores by greater than one standard deviation for all scales, compared with those adopting higher avoidance coping strategies. A more active coping style significantly increased scores for the PCS and MAQLQ-M, but had no effect on MCS scores. However, active coping and satisfaction with illness were significantly correlated with each other ($r = .43$, $p < .0001$). Lower asthma self-efficacy significantly reduced MCS and MAQLQ-M scores, but not PCS scores. The effect of economic circumstances on QOL was measured by the items concerning financial difficulties over the past 12 months, and whether concerns about costs had caused a delay in seeking needed asthma care. The absence of either of

these events for individuals had a significant positive influence on all HRQL measures.

Multivariate models of HRQL are reported in Table 6. These continue to show a significant effect on all of the three HRQL scores with avoidance coping, self-rating of asthma severity and financial difficulties. Costs delaying care was a continuing significant influence on TOTAL MAQLQ-M scores. Satisfaction with illness/positive evaluations of asthma exerted a significant effect on MCS values. Active coping had a major influence on PCS scores, but its effect on TOTAL MAQLQ-M did not remain significant when the effects of other variables was taken into account, and its influence on MCS scores was then negligible.

It should be noted that the significant effect of asthma self-efficacy on MAQLQ-M scores seen in univariate analysis was not seen in the multivariate model as nearly all of the effect of this variable was confounded by the two economic variables. It can be seen from Tables 5 & 6 that the effect of avoidance coping on the SF-36 summaries was reduced by the addition of the economic variables and self-rating of severity, but the influence of avoidance on TOTAL MAQLQ-M was less affected by these variables. Avoidance coping was not affected by controlling for age, in contrast to both active coping and asthma self-efficacy, which were less influential when the model was adjusted for age. Social support, whilst postulated to be a factor influencing quality of life, was not significantly related to any of the measures. However, active coping was confounded by Social support, with its effect increased when Social support was included in the model.

Overall, 60% of the variance in PCS and TOTAL MAQLQ-M scores could be explained by the variables of avoidance and active coping, the two variables relating to economic status, and the individual's rating of their asthma severity. Over 50% of the variance in Mental Health component summary scores could be explained by avoidance coping, the economic variables, asthma self-rating, and the level of positive evaluations/satisfaction with

asthma. Clinical measures (FEV_1, symptom scores, bronchodilator use, inhaled steroid dosage) were added to the model to assess their contribution. FEV_1, when used as a continuous variable of percentage of predicted value for age and height, made no significant contribution to the model. When coded as a dichotomous variable with 60% predicted as the cut-point, there was a significant negative contribution to MAQLQ-M and PCS in those with the lower value. The effect of symptom scores was almost entirely accounted for by self-rated severity, and hence had no significant effect on HRQL. Frequency of bronchodilator use (40) had a small but significant effect on HRQL. The dose of inhaled corticosteroids was unrelated to HRQL in the multivariate model.

The correlations with change scores in TOTAL MAQLQ-M over 12 months and clinical and psychosocial variables, adjusted for age are shown in Table 7. These show significant associations between changes in scores and baseline levels of avoidance coping, confidence/self-efficacy in asthma management, financial difficulties over the 12 months, cost concerns delaying care, and gross household income. Change in symptom scores and change in FEV_1, were also significantly associated with change in MAQLQ-M, as was a general assessment of whether an individual's asthma was improving or not. A random effects model showed a significant relation to changes in TOTAL MAQLQ-M scores for avoidance coping, cost concerns and financial difficulties, and rating of change of asthma severity (Table 8). For the PCS, only avoidance and financial difficulties were significant predictive variables of changes in scores (Table 8).

Results of the changes in MAQLQ-M sub-scales over 12 months for upper and lower thirds (tertiles) of the distributions of the avoidance and active coping scales and the self-efficacy scale are given in Table 9. This table also contains the comparisons in changes with time for the Yes/No answers of the questions about financial difficulties over 12 months and cost concerns delaying asthma care. The results show large, statistically significant differences in MAQLQ-M score changes for high and low avoidance coping

groups. All sub-scales showed improved scores for the low avoidance coping group, whilst the high avoidance tertile declined in all areas. The improvement was most marked in the MOOD domain. For the smaller subgroup with very high avoidance coping style (n=42) the decreases in MAQLQ-M over time ranged from 0.59 to 0.82, with deterioration most marked in the SOCIAL sub-scale. Significant differences were also seen for those who did or did not have concerns about costs that caused delays in seeking care for asthma. This was particularly marked for the BREATHLESSNESS domain. For the other variables, a significant difference was seen for changes in the MOOD sub-scale between those with and without financial difficulty, and also in the BREATHLESSNESS domain between upper and lower thirds of the self-efficacy/confidence scale. There were no differences in MAQLQ-M score changes between more or less use of active coping strategies.

The frequency of bronchodilator reliever use was significantly associated with avoidance coping, asthma self-efficacy and TOTAL MAQLQ-M scores, as well as self-rated asthma severity (Table 10). The model containing only these variables explained 59% of the variance in reliever use. Active coping, which showed significant univariate correlation with reliever usage, was not significant in the multivariate model. Removing the self-rating of severity from the model reduced the explained variance to 46%. Any effect of lung function and symptom scores was subsumed by self-rated severity.

Self-reported medication adherence was not related to any of the QOL measures (Table 11). A regression of self-reported adherence, controlled for age and the tendency to socially desirable responses (41), showed 42% of the variance could be explained by a combination of avoidance and active coping, medication side-effect concerns, level of social support and whether a person felt they took their medication in the manner it had been prescribed. Self-reported adherence was not related to knowledge about treatment, or of when to take medications such as inhaled corticosteroids, or to an expressed dislike of needing to take regular asthma medication. (42,43)

Discussion

Health-Related Quality of Life

The term quality of life is often used to signify a variety of domains, including functional status, impairment, disability and handicap. (44) It has been suggested that the focus on 'quality of life' has detracted from a fuller understanding of the role of specific psychological and social factors on chronic illnesses, such as asthma. (45) The patient retains authority over their own private symptoms, mood, and cognitions of health and illness. This points up issues concerning the extent to which HRQL instruments reflect disability or handicap. Disability involves the performance of behaviours determined by specific environmental tasks and relates to individual abnormalities. Handicap refers to the performance of social roles that can vary widely between individuals. (32) To the extent that measures of health status assess handicap then the role of psychosocial factors and the social environment will influence the ability to perform roles and tasks, and hence HRQL scores. (28,45) Both the MAQLQ-M and the SF-36 clearly measure handicap in addition to disability. Both scales assess social functioning and the effect of mood status on perceptions and on role functioning, in addition to areas such as breathlessness. This reflects the processes used to construct these instruments such as focus groups and other techniques that sought to include the perspective of the patient in determining what is important in quality of life. (34) Further, examination of items shows that scores for both will be strongly influenced by individuals' reporting what they choose to do, more that what they may be ultimately capable of doing. One of the important roles ascribed for HRQL tools in conditions such as asthma is that they can distinguish between the experience of dyspnoea or wheeze and the effect on activities, in a way symptom or lung function measures do not. (33) It cannot be assumed that high levels of reported breathlessness necessarily correlate with reductions in activity, and certainly not with the perception of the need for treatment. (46-48) There is an inherent variability

in the roles, behaviours, life styles, expectations and resources that characterise people's lives. (32) The MAQLQ-M and the SF-36 tacitly acknowledge this by often phrasing items in such a way as to allow the respondent to determine exactly what it is that causes the limitation, in a way that highly task oriented instruments do not. It is therefore not surprising that psychological and social factors may influence the scores obtained for both measures. From the perspective of making the patients' viewpoint of prime importance, it is of less consequence whether these factors affect airway functioning or rather the perception of health and quality of life. Determining which psycho-social factors affect HRQL, and the manner in which perceptions and physiology interact with disability and handicap becomes a pivotal research issue. This study has contributed to the small body of literature that examines the influence of psychological and socio-economic factors on HRQL in asthma.

Summary of Results

The results showed a significant effect of age on the MAQLQ-M and on the PCS, but not on the MCS of the SF-36. Gender had a minor effect only on the SOCIAL and CONCERNS sub-scales of the MAQLQ-M. The differences over time in the MAQLQ-M and the PCS were very small and probably not of any clinical importance despite their statistical significance. Similarly, the statistically significant difference between the TQEH and the LMHS over time in the PCS was very small, and very unlikely to be of clinical importance. Avoidance coping, which is manifested by wishful thinking and withdrawal from social relations and engagement with the world, was the major explanatory variable of HRQL scores. It was not affected by age or gender, and was less affected by economic circumstances than any of the other psychosocial variables. As seen in Chapter 9, it is also a significant predictive variable for hospital admissions with asthma. Socio-economic variables were also significant predictive variables of HRQL, as was the individual's perception of their asthma severity. Mental health was affected by the level of positive evaluations, or satisfaction with asthma, made by

people. Changes in HRQL were also related to avoidance coping and cost concerns, as well as global ratings of change. The self-report measure of adherence in this study was not related to quality of life or other outcomes.

Some authors have questioned the validity of aggregating scales in HRQL instruments. (32,49) Others have noted that changes may occur in one or other of HRQL domains or sub-scales in clinical trials. (33,50) If change occurs in all aspects of quality of life then aggregating scores will be useful. In asthma it is possible that physical changes will predate attitudinal changes and hence different domains will record different results. Alternatively, temperament, personality and coping abilities will effect such sub-scales as concerns, mood and mental health with scant regard for asthma severity. The results showed that such changes that did occur were relatively uniform across the sub-scales of the MAQLQ-M and in both SF-36 summaries. This may reflect that this was not a drug trial aimed at primarily improving symptoms over a brief period. It suggests that over reasonable length of time (1 year) changes can occur in all aspects of individual's HRQL. The high correlations between sub-scales, the high internal consistency values and unitary factor structure are all consistent with the view that HRQL can be viewed as a general construct. It will be valuable in specific instances to use the domain scales to examine the impact of interventions on particular aspects of HRQL. The similarity of scores for the two components of the SF-36 and for all the sub-scales of the MAQLQ-M may reflect the characteristics of the sample population. Mental and physical health are probably more closely interlinked in those requiring hospitalisation or judged severe enough to warrant hospital-based care, than would be the case for a healthy population. (51)

Simon and colleagues have argued that the assumption that mental and physical functioning are distinct phenomena would only be justified if the physical impairment reported by, for instance, depressed patients represents a negative cognitive bias rather than true functional limitation. (52) The construction of the summary scales of the SF-36 (factor analysis with

orthogonal rotation) results in some negative scoring coefficients being used to compute the summary scores. Hence, mental health scales make a modest negative contribution to the PCS, and physical scales likewise to the MCS. (53) Simon and colleagues showed that the potential effect of this can be paradoxical. In a trial of treatment for depression that brought about large gains in mental health and modest changes in self-reported physical health, the summated PCS was unchanged. The moderate improvements in the positively scored physical sub-scales were completely offset by large gains in the negatively scored mental health sub-scales. (52) They recommended alternative scoring methods be explored for the use of the SF-36 summary scores in longitudinal trials. This phenomenon had little impact on the results of the present study, as little changes were seen in any scales of either HRQL measure. The similarity of scores across all scales would suggest that future studies may need to explore alternative scoring methods for the SF-36 summary scales in longitudinal trials on populations of hospital-based asthma subjects.

Demographics

The influence of age on HRQL was not surprising, this relation has been reported frequently for both asthma-specific and generic HRQL instruments. (34,53,54) The importance of controlling for age and occupational status has recently been demonstrated for the physical health scales of the SF-36. (55) The absence of an age effect on the MCS is also consistent with previous data. (53) The lack of an effect of age on MOOD sub-scale scores would further support the view that the effect of asthma on emotional and mental health is consistent across age groups. Thus although mental health is significantly reduced in this sample of asthma subjects compared to the general population and with a community sample of people with asthma (as demonstrated in Chapter 4, 'Validity of two health-related quality of life instruments in asthma'), no age group is spared. The other three domains of the MAQLQ-M showed greater impairment with advancing age. This contrasts with the findings of Marks and colleagues who reported increased

social disruption in older patients and greater concerns for health in younger subjects. (34) Although plausible reasons for the trends described by Marks et al can be advanced (eg dyspnoea reducing activity in the elderly, and chronic illness causing worries for the young), equally cogent explanations can be made for opposite findings (eg reduction in sporting opportunities for youth, and the prospect of increasing risk of death in older patients). It is probably not surprising that these trends are sample dependent, and less likely to be a consistent feature of the asthma population.

The study design also did not completely control for co-morbidities in an additive fashion or assess the overall severity of co-existent conditions, which tend to impact more as age increases. In addition, the relation of age to scores emphasises the "health-related" nature of the "health-related quality of life" measures. To imply that physically disabled or elderly persons necessarily have poorer "quality of life" than younger individuals because of those physical limitations has normative implications that may be inappropriate and may tend to "reinforce stereotypes that underlie discriminatory practices". (56)

Avoidance Coping, Denial and Adherence

Coping occupies a position between the physical aspects of disease and its consequences. (45) Hence it is a prime target for research on psychosocial variables that affect self-reported quality of life. In a condition such as asthma, where self-management has a critical bearing on the manifestations of illness and on the history of an individual's condition, coping may be assumed to be important. Hence its neglect in the asthma literature is curious. Apart from the early work from Kinsman's Denver group two decades ago, and some interest from Dutch researchers, coping has been less prominent in the asthma literature than more conventional psychiatric categories such as depression, or aspects of the health belief model, such as self-efficacy. When comments on coping have been made, they have tended to concentrate on methods of coping with acute asthma attacks, rather than

with chronic self-management. Hence the concept of 'panic-fear' has received prominence in much of this literature. Little work has been done with the concept since asthma has been regarded as a chronic condition requiring regular preventive medication. Few studies have examined the influences on maintenance treatment, and less work relating these psychosocial aspects to patient outcomes.

Roth and Cohen have commented that although the area of coping is broad and complex, there is a striking coherence in much of the literature. (57) They note that two concepts are central to the understanding of coping: approach and avoidance. These are metaphors for cognitive or emotional activity that is oriented either toward or away from stress or threat. The effectiveness of these styles varies depending on the time frame and on the degree of potential control possible over the situation. Denial may be used by individual's to prevent them from being overwhelmed by previous stressful events, e.g. life-threatening asthma attacks. (58) However, the use of approach-type strategies at the onset of an acute asthma attack has been reported to reduce the number of severe attacks compared with the use of avoidance. (59) The use of denial or avoidance-type coping approaches has been reported to have a negative effect on following treatment recommendations in the long term. (60,61) This relates to another formulation of the approach-avoidance dimension of coping, where the concept of 'working through' or 'acknowledging' stressful material allows it to be 'integrated' and a more active orientation toward it achieved. (57,62) The potential impact on maintenance medication adherence and self-management of distancing and failing to move toward acceptance of a chronic condition is significant. (63,64) The coping measures of avoidance, denial and active / approach coping were chosen for this study because asthma self-management is an area of medical treatment where an active, task oriented style is needed for proper treatment. Avoidance or denial is likely to prevent any appropriate action. The influence of these on outcomes is thus of interest.

Self-reported adherence was only weakly correlated with avoidance coping ($r = 0.14$, $p = 0.047$), although when controlled for socially desirable response bias this association become stronger ($r = 0.23$). Any relationship between these two variables would require a more objective measure of adherence, such as electronic devices, to accurately determine its strength. The regression of adherence on avoidance and active coping, controlled for socially desirable responses, showed both coping styles were significant predictive variables. This would suggest that "positive" coping behaviours are as important in influencing compliance than the "negative" impact of avoidance coping. However, the self-report measure of adherence, despite its low demand characteristics (see Chapter 3), may be so inaccurate as to render any interpretation of its meaning purely speculative. The importance of these results lie in the fact that avoidance was much more strongly associated with HRQL outcomes, both cross-sectionally and longitudinally, than was active coping. It can be assumed that adherence is an important mediating behaviour through which coping strategies affect quality of life. Keefe and workers have suggested that employing problem-focused coping may be less important in managing chronic problems than not using negative coping strategies. (65)

The weak to moderate associations seen with avoidance coping and adherence may be due to inaccurate measurement of adherence, but may also reflect patient perception of their medication prescription. Conrad has identified destigmatisation as style of medication self-regulation. (66,67) Individuals who feel asthma stigmatises them as chronically ill are reluctant to use regular medication as this confirms their infirmity. (67) Stigma has been identified as a factor related to asthma morbidity. (68) The adherence scores in this study were not significantly correlated with knowledge about how and when to take asthma medications. However, self-reported adherence was related to the belief that the individual was taking their treatment as it had been prescribed. The lack of an association between these two apparently connected ideas suggests that some other factors come into play. The use of wishful thinking and a refusal to accept the identity of "asthma" has been

associated with a denial of the need for regular medication and a misconception that maintenance medication was not necessary or that it had not been prescribed. (64) How accurately patients' understand what their medication prescription is has been linked to closer adherence to that treatment. (43) Thus it is possible that high avoidance coping is closely linked with not taking regular medications, and that high-avoidance individuals do not accept 'asthma' as part of their self-identity. This coping strategy may be associated with individuals not accepting that they have a condition that requires regular medication, and with not acknowledging that there has been a recommendation for regular use to which they can then be non-adherent.

Chronic avoidance of asthma will also reduce effective self-management. This type of coping style has been likened to a grief model of illness adaptation in which patients may refuse to pursue illness management approaches because they irrationally seek a medical "cure". (69) The implications for asthma self-management and maintenance medications is clear. The defensive strategy of refusing to accept the label of asthma and disengaging from the chronic nature of the condition, needs to be distinguished from phobic avoidance of feared situations or trigger factors. This is a separate but potentially significant problem. (70) This aspect of 'panic-fear' has not been assessed in this study, although it should be noted that scores for the 'anxiety' item in the MAQLQ-M were not reduced compared to other items.

High denial (71) scores have been found in severe asthma patients in a number of reports from differing countries, indicating it is potentially a key concept in understanding the psychological aspects of life-threatening asthma. (72-75) Denial was not found to be significantly associated with HRQL in this study. In contrast to the denial scale, the measure of avoidance used in this study focused on an individual choosing to avoid directly confronting their problems, on wishful thinking, and on indulging in comforting behaviours rather than problem solving. * Although modestly related to each other ($r = .24$, $p < 0.01$), they appear to be measuring different domains. It

may be that denial is of greater importance in influencing behaviour during life-threatening episodes than in ongoing, day-to-day self-management, and consequently quality of life.

Mood states and psychological distress

Subjective quality of life scores can be influenced by temperamental or personality characteristics. (49) Reports indicate that some people bias their responses to be more socially acceptable. (41,76) This was not seen for the HRQL measures in the present study, where inclusion of the socially desirable responses score had no impact on any of the models. Studies have indicated that neuroticism (49) or negative affectivity (77), correlate strongly with self-report health status scales, without necessarily predicting future health states. Hyland et al found that in asthma subjects a construct of evaluations or emotional distress of illness correlated more strongly with neuroticism, compared with perception of functional limitations or disability items. (78) Kempen et al reported unique contributions of neuroticism, mastery and self-efficacy to HRQL, which was particularly marked for mental health. (79) Correlations between neuroticism and scores on the SF-36 have been reported. (49) Watson and Pennebaker suggest that health complaint scale scores reflect a pervasive mood disposition of negativity, as well as the expected, organically valid, component of health. (77) Barsky et al found that self-ratings of health were closely related to individual fears and beliefs about disease, and a tendency to somatatise distress, in addition to functional impairment. (80)

Whether this is an effect of personality on true or perceived levels of HRQL is unclear. (79) Hyland and colleagues have suggested that the more a patient's response is determined by personality, the less likely the item is to detect change in a clinical trial, particularly a drug trial, as these do not manipulate personality. (50) Some theorists have assumed that differences

in coping style are intrinsically tied to personality differences. (81) Others have found that there is merit in studying coping preferences apart from personality traits. Carver and colleagues have indicated that people tend to adopt certain coping tactics as relatively stable preferences, with less influence from stable personality traits. (81) They have suggested that taken overall, the research is consistent with the view that coping dispositions and personality traits play complementary roles in situational coping. The significance of finding strong associations between coping styles and HRQL in asthma is that these preferences may be more amenable to manipulation in specific interventions than personality traits. The relation between avoidance coping and changes in HRQL with time further emphasises the potential of focusing attention on coping styles in intervention studies.

Some cautions could be noted in interpreting these results. Common method (i.e. questionnaire) or agent (i.e. self-report) variance measures could have contributed to the linkages found. This is particularly true as personality factors, such as neuroticism, were not controlled for in the study design. This concern is alleviated somewhat in the prospective design used here controlled for initial functioning. As Carver and associates explained, "if neuroticism acts to predispose people to distress, it follows that the best proxy for neuroticism is distress itself". (81)

High levels of depression can influence perceptions of functioning, as well as lead to restrictions on social activities and to social isolation. (49) Low mood may also effect coping skills. (82) Psychological variables such as depression and anxiety have been found to be associated with functional status measurements in chronic illnesses (45), and also with scores in the St. George Respiratory Questionnaire (SGRQ) in chronic asthma subjects.(83) It has also been reported that an inhibited type of stress appraisal, along with a coping pattern of wishful thinking and avoidance, occurs in depressed patients. (84) The absence of a measure of depression in this study could lead to criticism of the validity of the findings. One difficulty with scales measuring depression in asthma is that they frequently include items that can

be positively scored due to physical illness rather than mood change. (82) These include items on fatigue and sleep disturbance, both of which are common in asthma, particularly as severity increases. (85) One technique is to remove these items, but this also reduces the possibility of applying a cut-off to assess clinical depression. The use of a formal clinical structured interview to accurately assess patients' for depression, was not a feasible option in this study. Examination of the item scores for the MOOD sub-scale of the MAQLQ-M emphasises the difficulty here (Figure 1). The score for fatigue (Q9, Figure 1) was the lowest of all but one of questionnaire items. The other items in the MOOD scale (Figure 1 Q10-14, sleep disturbance, depressed mood, anxiety and frustration) were all close to the overall mean. If depression was an overwhelming feature of this sample of asthma patients one would expect the MOOD score to be very low. However, scores were consistent across the sub-scales. The SF-36 allows comparisons with other conditions in order to judge the level of comparative impairment from emotional and psychological problems. In the SA Omnibus study those in the community with a severe GHQ score indicating psychiatric caseness (n=164), had a MCS score of 31.1, compared with the population in the present study, which had a MCS score of 39.6, a significant difference of approximately 0.8 standard deviation units. (86) Data from the US has indicated that a score of 52 on the Mental Health (MH) scale of the SF-36 is the optimal cut-off for detecting depression in the general population. (53) Around 15% of the present study sample had scores below the cut-off score of 52 on the MH scale. This level is in the range reported for the general community for the prevalence of depression. (53,87) Furthermore, in standardised terms (ie compared with population norms) the scales of Social Functioning (SOC) and Role Limitations-Emotional (ROLE) showed greater reductions that the MH scale. These two scales have a narrow focus and weak scaling properties, and it is possible limitations of the scales in measuring functioning in these areas have been a contributing factor to the low MCS scores.

This is not to say that mood problems were not factors in the morbidity of this population. Kolbe and co-workers found considerable psychological morbidity

in patients' admitted to hospital with asthma, but there were no differences between those with life-threatening attacks and those with less severe attacks. (88) Early studies have indicated a high prevalence of psychiatric "caseness" in those with very severe asthma attacks. (73,89), although others have not been able to identify specific disorders that are associated with how people with asthma score their symptoms. (48) Epidemiological studies have shown that 26% of the general population have a current psychiatric disorder, and this will need to be taken into account by clinicians' managing physical illness. (87) It is likely that there a variety of psychological and emotional problems that are associated with asthma morbidity. It may be that studies that examine "caseness" in a more general sense pick this up, where attempts to be more specific lose statistical power. Forms of psychosocial distress such as helplessness, poor self-esteem, uncertainty, loss of control and low self-confidence fit less well into conventional psychiatric categories, but are likely to occur in chronic conditions such as asthma. (45) The strong relationship between coping strategies seen in this study is consistent with work on other illnesses (90). It could be speculated that is because coping behaviours are a final or 'common pathway' through which a wide spectrum of mood states, and personal attitudes and beliefs, exert their influence over the consequences of having a condition such as asthma. The importance of avoidance as a predictive variable of HRQL, and not just as an epiphenomenon, can be seen in its strong association with longitudinal score changes. Future research should address the question of the relationship between avoidance and depression, utilising clinical interviews in addition to survey tools.

The complexity of many psychological instruments, their length, and difficulties in administration and interpretation, have precluded these measures from entering the clinical domain of patient care. (82) The advantage of the tools used in this study, which were found to be strongly predictive of quality of life, and of changes in HRQL, is their brevity and ease of interpretation. Using a total of 15 questions, (including the coping styles, economic questions, and self-rating of severity), it was possible to predict

60% of the variance in asthma quality of life. These items were also significantly associated with changes in QOL scores over 12 months. Wolfe, writing in relation to arthritis, has recommended the use of tools that can be used in the clinic to measure disease status, but which when used in combination also quantify psychosocial distress. (82) The combination of the 15 psychosocial variables, plus the 22 item MAQLQ-M, would provide an easily administered and interpreted tool to achieve this aim in asthma patients. The addition of a simple query regarding previous emotional counselling as used by Kolbe and workers (19), could enhance the effectiveness of this tool. Bukstein has indicated that the use of a point-of-care 'asthma report card' led to increased numbers of psychiatric referrals. He noted that in patients who had stable clinical disease markers but reported feeling their asthma was "really bad and my energy is down", physicians learnt to look for depression.(91) It should also be noted that the HRQL tools and avoidance were significant predictive factors for hospital admissions and emergency department attendances (see Chapter 9).

Positive evaluations of illness and mental health

The SF-36 MCS was significantly related to the Satisfaction with Illness Scale. This scale of positive evaluations of health measures positive ways in which asthma has contributed to the patient's life. (92) Hyland and workers have indicated that positive evaluations is an independent construct underlying quality of life judgements in asthma, and is correlated with extraversion, but not neuroticism (78) These authors concluded that being extrovert and unable to engage in social activity due to illness is a liability which is not the case for people who are well. (78) Although extraversion was not measured in this study, this formulation would allow an interpretation of how more or less positive evaluations of asthma impact predominantly on mental health. The population in the present study had as great a reduction in MCS as PCS scores, with a mean reduction of approximately one standard deviation unit from the population norm. Of the four SF-36 scales that contribute to the MCS, the largest reductions in standardised terms (ie compared to the

population norms), were the Social Functioning (SOC) and Role Limitations-Emotional (ROLE) scales, rather than the Mental Health (MH) scale. Whilst these scales have generally weak scaling properties and are narrowly focused (51), impairments in these areas would be consistent with the above hypothesis. Asthma appears to be associated with a significant effect on mental health. In the Medical Outcomes Study, asthma was the only condition other than depression that was associated with significant negative effects on the Mental Health Component Summary scores of the SF-36 Health Survey, albeit with a small sample size of subjects with identified asthma. (53) Satisfaction with illness scores did not have a significant impact on PCS or MAQLQ-M scores. Reformulating the perception of illness in a positive way may be a part of a process of cognitive restructuring that improves mental health and translates into a more general satisfaction with life. If true, this would also suggests a direction by which the 'bother' of asthma may be ameliorated, without necessarily affecting physical illness. Conversely, it may be that less positive evaluations of the effect of asthma is one of the reasons that improvements in physical condition do not necessarily lead to improved perceptions of health. (93)

Active coping, social support and self-efficacy

The interaction between social support and coping styles may also be a factor in determining health status. It had a confounding effect on the influence of active coping on HRQL. The strategy of dealing with stress by task-oriented, problem solving approaches of seeking out information and making forward plans is likely to be enhanced by a greater degree of perceived support from close associates or family, and diminished by feelings of isolation. (94) The sense of mastery which may follow from this coping approach can also be enhanced by strong supportive relationships. (95) Henderson has pointed out that the social support received by an individual is at least partly dependent on that persons behaviour in maintaining social relationships. (96) Hence frequent use of avoidance strategies and withdrawal from the world may further diminish levels of social support. Given the data showing consistent

effects of low social support on health outcomes (94,97,98), this maybe another means by which coping styles could exert an influence on quality of life, and other morbidity measures. As Locker states, "We know little about the development of social isolation and the fragmentation of social networks following the onset of illness and little of the ways in which individuals might be assisted in retaining old or creating new social support systems". (99)

Active coping was a significant component of the explanatory model for PCS when controlled for age, and there was a trend towards an association with TOTAL MAQLQ-M, but not with MCS scores. The relationship with MAQLQ-M in particular was affected by age. The behaviours that make up the active coping style, questioning experts and seeking information and solutions to problems, have previously been reported to be increased in middle aged adults compared with either younger or older people. (100,101) Social support may interact with active coping in a number of ways. Individuals who perceive greater social support may be encouraged to assert opinions, seek information, and be more combative in regard to their asthma. (17) On the other hand, people who adopt a more active, problem solving approach may attract or demand greater support from their social network. Individual aspects of behaviour are integrated into a person's sense of self and of belonging to a particular social group. (102) Social isolation or lack of support for behaviour change from the person's social environment can be powerful factors working against change. As Byde has said, "individual behaviour change is extremely hard if it requires social isolation as well". (103) On the other hand, supportive associates can be used as sympathetic ears to ventilate feelings, which may not be always adaptive. (104) Self-management programs encourage a coping style which can be characterised as problem-focused.(105) The lack of a significant association in multivariate analysis between active coping and improvements in HRQL over time, and the confounding by social support and illness satisfaction, would bring this approach into question. In practice it has been noted that few education programs develop problem-solving skills as distinct from providing a list of recommended actions to take in certain situations. (106,107) It may be that it

is necessary to address negative attitudes such as avoidance, or basic economic disadvantage, before attempting to teach these positive self-management skills. (19,65) This would be consistent with the principles of a hierarchy of educational needs. (106,107) Psychologically, it would be consistent with the association of avoidance, behavioural and mental disengagement, anxiety and helplessness. (81) Tactics such as daydreaming, escaping into TV or comforting activities like smoking seem linked to the expectation of poor coping outcomes, and make active or problem-solving approaches less likely to be pursued. (81,104) The negative correlation between active and avoidance coping ($r = -.32$, $p < .0001$) lends some support to this contention. However this association does not show whether there is a hierarchy or order to coping, and if it is necessary to suppress 'negative' styles to allow others to flourish or vice versa. Intervention studies addressed at specific coping approaches are needed to answer this question, and the issue of to what extent active coping is a mediator of the effect of social support on outcomes. In addition, the relatively modest strength of this association is also consistent with previous work on healthy undergraduates that showed that people dealing with stress can simultaneously experience seemingly opposite coping impulses, such as acceptance and denial. (81) The question of the sequences of coping used by individuals has not been addressed in this study. Further work is needed to examine what the sequence of coping approaches used by asthma patients is, and whether this follows a pattern of stages which may then be amenable to stage-focused interventions.

Socio-economic disadvantage

That social circumstances influence attitudes and behaviour can be seen when self-efficacy and its effect on HRQL is considered. When examined in univariate analysis in relation to both baseline HRQL and in changes in scores, the level of confidence a person has in managing their asthma has a significant impact. However, this effect is almost completely confounded by the level of economic problems an individual is experiencing. Osman has

pointed out that the various recent studies of management interventions have usually not investigated whether successful outcomes for patients are influenced by social factors. (67) The reported difficulties in recruitment and drop-out rates in studies of self-management programs (108-114), make the interaction between self-efficacy and economic status a potentially critical factor in designing such programs. In the face of economic disadvantage, teaching self-management skills in isolation, a major component of current 'best practice' asthma management (25,115), will most likely be inadequate for the task of improving outcomes. Self-efficacy, although increasing the likelihood someone will attempt a task, does not ensure behaviour will follow, although it may be a necessary prerequisite for performing the behaviour. (116-119) Perceptions of barriers to performing actions has been shown to be the most powerful of the health belief model's dimensions in predicting behaviour. (120) It would seem from the data that cost barriers are a significant impediment to management in asthma patients, and this has a major impact on quality of life. A more complex trial design that attempted to alter self-efficacy and cost barriers separately or in a stratified group design would be needed to examine this issue.

The use of questions specifically targeting costs of asthma causing delays in seeking care and financial hardship has the advantage of focusing directly on the impact of economic factors on asthma, rather than a broader category of socio-economic status (SES). More conventional variables such as income, education and job category were examined as part of the initial models, but were found to be less useful than the specific questions in interpreting the data. In a diverse sample, with many students, elderly and retired persons, unemployed as well as employed subjects, this may avoid some of the problems that could arise in using only income, educational status or postcode area in assessing socio-economic status. It also potentially means that the effect of some of the psychosocial variables can be more clearly examined for their direct effect on quality of life, rather that as effector variables of socio-economic status. In addition, it helps to make clearer what aspects of socio-economic disadvantage relate to HRQL, and how SES

impacts on psychological factors. This point can be better understood if the different effect of concerns about asthma costs on general HRQL (SF-36) is compared with the disease-specific instrument (MAQLQ-M). Cost worries delaying asthma care was not part of the multivariate model for the SF-36, but explained a significant proportion of the TOTAL MAQLQ-M score. Similarly, it was able to predict changes in all of the sub-scales of the MAQLQ-M over 12 months, which the item regarding general financial difficulties did not do. Those who did not have cost concerns that delayed care fared significantly better over 12 months than those who did delay care due to worries about the cost. This was particularly seen in the BREATHLESSNESS domain. This suggests that it may be simply via not purchasing medications and puffers that this effect is seen. The addition to the clinical interview of such questions as, "Will you be able to afford the medications?", could be used to test this hypotheses. (121) A recent study from a South Australian country centre found that 30% of prescriptions written by General Practitioner's were not taken to the chemist, and that this primary non-compliance was more likely in patients from low income groups. (122) Additional costs, such as paying for help at home or child-care during asthma episodes, may also not be affordable for many people, and cause delays in seeking care. It should be noted that delaying seeking care because of concerns about missing work due to asthma was not associated with HRQL.

The difference between the impact of general financial difficulties and specific cost concerns on HRQL may be due to differences in priorities of some patients, who have to make choices about spending options. Alternatively, some people may manage well in relatively straitened circumstances until an unusual problem occurs, eg an acute asthma episode, and may not have the wherewithal to cover the increased costs. The differential could also be an indicator of how some people value health relative to other options for spending money. It is possible to delay seeking care for asthma due to a dislike of spending money on health products even if one could easily afford to spend such funds. The self-report of how highly the person valued health was not related to any of the HRQL measures or to the cost questions. The

influence of avoidance coping may occur via individuals' not accepting that their asthma requires money to be spent on care. Control and the power to choose, is constrained for those with fewer material resources. (123) If choices about life are limited, then immediate comfort or ease outweighs long-term benefits. (124) The inconveniences of health behaviours such as trigger avoidance or daily medication, are then not worth bothering about. Thoits has noted that much stress research has tended to disregard or deemphasize the degree to which individuals are activists on their own behalf. (125) But individuals' activism and motivation become obvious when coping strategies are studied. In these circumstances it is possible to lose sight of the structural constraints on people's agency. (125) For problem-focused coping to be effective subjective appraisals must match the objective controllability of the situation. In asthma it tends to be assumed that as medication and trigger avoidance are usually effective, then "controllability" is not an issue, which ignores what specific structural constraints may exist. Future work should seek to define the specific nature of socio-economic constraints on effective asthma care.

Bronchodilator usage

A relationship has been noted between the amount of bronchodilator (BD) used and the severity of an attack. (126,127) No definite explanation has been proven for this association, but it is possible increased dose of *B* agonists worsen the severity of an attack or delay patients seeking help in an attack. (128) Clearly those who perceive more symptoms will tend to increase BD usage. The question remains if other factors influence both symptom perception and the consequent behaviour. The work of Kinsman and colleagues indicated that anxiety, panic-fear, and feelings of either helpless dependency or inappropriate independence were associated with misuse of medications. (129,130) This work was questioned by Maes and Schlosser, who found severity and coping styles to be of greater significance in hospitalisations. (14) The population in the present study differed from either of these other groups in that, although not a randomised sample, it

contained a broader range of severity. Unlike the Denver patients', the majority were not admitted to hospital over the study period nor required oral steroids either continuously or episodically. This data suggests that differences in coping, self-efficacy, and general quality of life have a significant impact on bronchodilator use, independent of actual symptoms or lung function. The addition of self-rated severity, which may include an individual's assessment of symptoms but also include a broader and more subjective evaluation of the effect of asthma on their lives, produced a model that explained the majority of variance in reliever use. The question of how much the perception of severity is influenced by the frequency of the need to take relievers is unclear. It may be that frequent reliever use is a habit more closely related to general beliefs about disease severity (as measured by MAQLQ-M), and its controllability (as assessed by self-efficacy and coping) than with the actual frequency of symptoms or lung function. It can be argued that MAQLQ-M scores reflect symptom severity, but TOTAL MAQLQ-M measures a much wider range of issues than just symptoms. As has been shown, it is also modestly related to lung function and symptoms (see Chapter 4). It could also be argued that stratifying for disease severity on the basis of symptoms or lung function would be a more valid form of analysis. However, the intention was to examine if patient belief's and attitudes were significant determinants of BD use, irrespective of lung function. The data suggests that addressing these beliefs about symptom control and medication, and negative coping styles, may increase appropriate bronchodilator use.

The data also shows that the factors associated with HRQL are also determinants of BD use. One interpretation of the strong association of avoidance coping and both HRQL and BD use is that individuals' attempt to maintain self-identity (64) or 'psychic equilibrium' via disengagement from asthma, but that this has physical consequences. The need for bronchodilators to relieve symptoms intrudes into daily life, but does not necessarily prompt any further cognitive or behavioural action to control these symptoms. Some support for this view is given from the modest positive

correlation between BD use and reported daily inhaled corticosteroid (ICS) dose ($r= .29$, $p< .0005$). The positive correlation would indicate that this association is not merely due to adequate preventive medication precluding the need for the use of reliever medication. The relative weakness of the association indicates that higher need for bronchodilators does not automatically translate into higher doses of prescribed ICS. This could possibly be due to inadequate prescription of ICS medication due to the treating physicians' failing to recognise the extent of the problem. Conversely, it may be that attending physicians' were able to recognise in many cases that BD use was disproportionate to the severity of disease and further dose increases were inappropriate. In the study population, 83% of those experiencing asthma attacks more than weekly were taking inhaled corticosteroids at some dosage, 67% were taking over 1000 mcg/day, and a further 21% were taking oral corticosteroids. This would seem to caution against excessive optimism that excessive BD use can be easily reduced by the simple expedient of increasing the prescribed inhaled corticosteroid dosage. Given the complex interaction between the use of avoidance coping strategies, or feeling low self-efficacy, and of not using active problem-solving approaches, the problem would seem more likely to be a function of attitudes of disengagement, helplessness, and avoidance, as simply due to more severe disease. Whether managing physicians' can adopt certain practices to alter this is a separate issue, deserving further research.

Conclusion

With regard to the hypotheses stated at the beginning of the chapter, the results showed that clinical and psychosocial factors both have an important influence on HRQL, in this selected group of patients from two hospital clinics. Avoidance coping and financial disadvantage were associated negatively with HRQL as expected. However, self-efficacy was not an independent factor in explaining HRQL, and active coping was significantly associated only with PCS scores in the multivariate models. Social support did not have a significant independent association with quality of life.

Chapter 9, indicates that a number of psychosocial variables are also related to hospital admissions for asthma. Nonetheless, it is difficult to be certain to what extent the effect of psychosocial variables on HRQL scores relates to actual health status or perceived quality of life. Some authors have suggested that, ideally, subjective indices of health should not be influenced by patient characteristics not directly related to disease and health care. Others have argued that quality of life is inherently subjective and that it is only because these measurements consider the patient's perspective that they have meaning or importance. (33,131) A synthesis of these two positions can be achieved if one begins to consider that various psychological, attitudinal, or even socio-economic factors are both integral to health, but also amenable to intervention. In this context, future work should focus on understanding more clearly how coping styles and economic disadvantage affects asthma. The relationship between these factors and disease activity, which relates to symptom intensity, airway obstruction and the amount of medication needed (132), warrants further study. Markers of physiological severity such as airway inflammation (as measured by such techniques as induced sputum analysis) (133), and with objective assessment of medication usage (as measured with electronic devices) (134), may be important to this understanding. The value of quality of life as an outcome tool in this area of research lies in its potential to evaluate the relative benefits to individuals of asthma control versus the 'bother' to patients of asthma management. (93) The interplay between perception of bronchoconstriction, and coping and appraisal of stress, and these influences on quality of life merits additional research work. Adequately identifying and controlling for psychiatric conditions such as depression or anxiety, possibly by using clinical interviews, is important in helping to clarify the impact of mood on asthma, and on coping mechanisms. The precise ways that the issues of cost impact on behaviour, such as the purchase of medications, and on other self-management behaviour, warrants further elucidation. The approach of physicians within the consultation and other issues of the organisation of care, such as length of consultations, and the relationship of these factors to

coping styles, the level of airway inflammation, and to objectively measured medication usage, is another potential area of research. How clinicians can influence the process of 'working through' from a position of avoidance to acceptance and active coping via mentoring or specific cognitive interventions, and the effect on outcomes is one such area of possible investigation. The advantage of using HRQL instruments as an outcome measure in such research is that it can assess the impact of interventions across the range of morbidity in ways symptoms or lung function alone cannot. Thus, the effect of cognitive interventions on emotional state or the distress experienced due to asthma can be examined separately from its effect on physical functioning. It is possible such interventions may reduce the 'bother' from asthma without altering functional status (93), and hence judgements as to their effectiveness, and especially their cost-effectiveness, would need to be made on this basis. A HRQL tool is a realistic means by which these judgements can proceed.

The evidence that short-term morbidity in children can be improved by interventions that focus on the phases of self-regulation, and that medication use can be reduced by dealing with the emotional 'bother' of asthma, suggests this may be an important area for management interventions to address. (135,136) Estimating coping strategies used by individuals may be a means of selecting which patients are more likely to be either in need of, or likely to benefit from, this sort of approach.

The use of quality of life instruments as outcome measures in asthma is surprisingly complex. The important role of psychosocial factors and their impact on measures of life-quality suggests the need for a more detailed examination of their role in any trial which reports HRQL outcomes. It would also indicate a need for more complex trial designs to be considered that control for some of these factors at the outset of studies. (45) Interventions specifically designed to address these issues warrant investigation. Psychological assessment can facilitate both cognitive-behavioural

interventions and tertiary prevention strategies that can help to preserve quality of life for persons with asthma.

Table 1: Definitions of measures used in the study.

Measure	No. of items	Definition	Alpha Baseline	Alpha Follow-up	Ave. inter-item correl.
Avoidance coping	6	Frequency an individual uses avoidance coping in response to health problems	.83	.84	.50
Active coping	6	Frequency an individual uses active coping in response to health problems	.79	.80	.38
General Adherence	5	Patient's typical tendency to adhere to medical recommendations	.88	.87	.60
Medication Dislikes	4	Dislike of using regular asthma medications	.78	.78	.44
Satisfaction Illness	6	Positive evaluations of illness' contributions to one's life	.80	.81	.35
Health as value	6	Agreement of the primary importance of good health in one's life.	.62	.65	.29
Socially desirable	5	Tendency to give socially desirable responses	.67	.66	.29
Self-efficacy	10	Confidence/Self-efficacy in personal ability to manage asthma	.77	.79	.28
Social support	7	Perceived level of emotional support available and level of social participation.	.79	.80	.32
Autonomy	18	Preferences for decision-making autonomy regarding treatment	.86	.88	.40
Participatory decision-making	3	Tendency for treating physician to involve patient in treatment decisions.	.80	.81	.58
Total symptoms	4	Summed score of symptoms	.80	.82	.45
MAQLQ-M	22	Disease-targeted quality of life	.97	.97	.58
SF-36	36	Generic quality of life	.93	.93	.54

Table 2: HRQL Scores by hospital and survey period.

Random effects GLS Regression

SF-36 Physical Components Summary (PCS)

	Coeff.	95% Conf.	Interval	p
Survey	.189	.056	.333	.005
Hospital	-1.19	-3.77	1.40	.37
Hosp_Survey	.37	.099	.636	.007
TQEH_survey	.39	.17	.61	.001
LMHS_survey	.035	-.127	.20	.67

SF-36 Mental Components Summary

	Coeff.	95% Conf.	Interval	p
Survey	.012	-.145	.17	.88
Hospital	-1.30	-3.87	1.28	.33
Hosp_Survey	.23	-.087	.55	.15
TQEH_survey	.13	-.099	.36	.27
LMHS_survey	-.089	-.306	.128	.42

TOTAL MAQLQ-M

	Coeff.	95% Conf.	Interval	p
Survey	.017	.003	.030	.015
Hospital	-.26	-.54	.02	.069
Hosp_Survey	.007	-.019	.035	.57
TQEH_survey	.02	-.009	.043	.06
LMHS_survey	.013	-.004	.03	.12

Note: Survey — Change in PCS/MCS with follow-up surveys

Hospital — Difference between hospitals (TQEH v LMHS)

Hosp_Survey — Difference between hospitals over time

TQEH/LMHS_Survey — Change in PCS/MCS with follow-up surveys at TQEH/LMHS

Table 3: HRQL scores by demographic characteristics

SF-36 Physical Components Summary (PCS)

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender[#]	-.62	-3.4	2.1	.66
Age* (n)				
35-44 years (41)	-4.2	-8.0	-.50	.026
45-54 years (43)	-5.9	-9.5	-2.3	.001
55-64 years (49)	-9.4	-12.9	-5.9	.000
65-74 years (35)	-10.1	-14.3	-5.8	.000
>75 years (6)	-14.4	-22.8	-6.1	.000
Survey**				
3 months	1.1	-.28	2.5	.12
9 months	2.2	.66	3.8	.005
12 months	2.1	.47	3.7	.012
Hospital[++]	-3.4	-6.0	-.82	.010

[#]Differences between Males and Females

*Compared with reference age group of 15-34 years. (n= 119)

**Change for each survey controlled for age

[++]Difference between hospitals (TQEH v LMHS) controlled for age

Table 3: QOL scores by demographic characteristics (continued)

SF-36 Mental Components Summary (MCS)

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender[#]	-.55	-3.3	2.2	.69
Age* (n)				
35-44 years (41)	1.2	-2.8	5.1	.56
45-54 years (43)	-.63	-4.5	3.3	.75
55-64 years (49)	.84	-2.9	4.6	.66
65-74 years (35)	.70	-3.8	5.2	.76
>75 years (6)	5.4	-3.7	14.4	.25
Survey**				
3 months	.11	-1.5	1.8	.89
9 months	-.04	-1.9	1.8	.96
12 months	.001	-1.9	2.0	.99
Hospital[++]	-1.3	-4.1	1.4	.34

[#]Differences between Males and Females

*Compared with reference age group of 15-34 years.

**Change for each survey controlled for age

[++]Difference between hospitals (TQEH v LMHS) controlled

Table 3: QOL scores by demographic characteristics (continued)

TOTAL Asthma Quality of Life Questionnaire

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender[#]	.13	-.17	.43	.41
Age* (n)				
35-44 years (41)	-.18	-.63	.22	.34
45-54 years (43)	-.56	-.99	-.14	.01
55-64 years (49)	-.61	-1.0	-.20	.003
65-74 years (35)	-.73	-1.2	-.26	.002
>75 years (6)	-1.2	-2.1	-.17	.021
Survey**				
3 months	.13	-.01	.28	.08
9 months	.21	..54	.37	.009
12 months	.17	.001	.33	.049
Hospital[++]	-.34	-.63	-.05	.023

[#]Differences between Males and Females

*Compared with reference age group of 15-34 years.

**Change for each survey controlled for age

[++]Difference between hospitals (TQEH v LMHS) controlled for age

Table 4: MAQLQ-M Domains by age, gender and survey

MAQLQ-M - BREATHLESSNESS

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender#	-.12	-.44	.20	.46
Age* (N)				
20-24 years (37)	-.23	-.93	.47	.52
25-29 years (40)	-.22	-.92	.47	.53
30-34 years (20)	-.56	-1.4	.25	.18
35-39 years (26)	-.30	-1.0	.44	.43
40-44 years (15)	-1.0	-1.9	-.16	.02
45-49 years (24)	-.66	-1.4	.11	.09
50-54 years (19)	-1.2	-2.0	-.40	.003
55-59 years (25)	-.57	-1.3	.18	.14
60-64 years (24)	-1.0	-1.8	-.29	.006
65-69 years (18)	-.74	-1.6	.07	.07
70-74 years (17)	-1.0	-1.8	-.16	.02
75-79 years (4)	-1.8	-3.2	-.40	.01
> 80 years (2)	-1.9	-3.7	-.04	.04
Survey**	.019	.003	.03	.018

#Differences between Males and Females, controlled for age.

*Compared with reference age group of 15-34 years.

**Change over time controlled for age

Table 4: MAQLQ-M by age, gender and survey (continued)

MAQLQ-M: CONCERNS

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender[#]	.36	.02	.70	.038
Age*				
20-24 years	-.017	-.91	.56	.65
25-29 years	-.11	-.83	.62	.77
30-34 years	-.46	-1.30	.39	.29
35-39 years	-.15	-.93	.63	.70
40-44 years	-.77	-1.67	.14	.09
45-49 years	-.54	-1.34	.26	.19
50-54 years	-.92	-1.77	-.07	.03
55-59 years	-.52	-1.28	.20	.20
60-64 years	-1.02	-1.81	-.23	.01
65-69 years	-.75	-1.60	.10	.08
70-74 years	-.80	-1.69	.07	.07
75-79 years	-1.45	-2.9	-.01	.04
> 80 years	-1.03	-2.98	.89	.29
Survey**	.017	.01	.03	.025

[#]Differences between Males and Females, controlled for age.

*Compared with reference age group of 15-34 years.

**Change for over time controlled for age

Table 4: MAQLQ-M by age, gender and survey (continued)

MAQLQ-M: MOOD

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender[#]	-.035	-.31	.24	.81
Age*				
20-24 years	.31	-.29	.91	.32
25-29 years	.02	-.57	.62	.93
30-34 years	-.06	-.75	.62	.85
35-39 years	.26	-.38	.90	.42
40-44 years	-.10	-.83	.64	.79
45-49 years	-.07	-.72	.58	.83
50-54 years	-.44	-1.13	.25	.21
55-59 years	.20	-.45	.84	.55
60-64 years	-.15	-.80	.49	.65
65-69 years	-.10	.78	.60	.80
70-74 years	.01	-.73	.70	.97
75-79 years	-.14	-1.32	1.0	.81
> 80 years	-.31	-1.88	1.25	.70
Survey**	.015	.001	.03	.034

[#]Differences between Males and Females, controlled for age.

*Compared with reference age group of 15-34 years.

**Change for over time controlled for age

Table 4: MAQLQ-M by age, gender and survey (continued)

MAQLQ-M: SOCIAL

Random effects GLS Regression

	Coeff.	95% Conf.	Interval	p
Gender#	.42	.05	.78	.025
Age*				
20-24 years	-.01	-.80	.78	.98
25-29 years	.04	-.74	.82	.92
30-34 years	-.46	-1.37	.45	.32
35-39 years	-.07	-.91	.77	.86
40-44 years	-.85	-1.82	.12	.09
45-49 years	-.48	-1.34	.38	.28
50-54 years	-.99	-1.90	-.07	.03
55-59 years	-.52	-1.37	.33	.23
60-64 years	-1.23	-2.08	-.38	.004
65-69 years	-.99	-1.90	-.07	.04
70-74 years	-1.05	-2.00	-.11	.03
75-79 years	-1.50	-3.05	.06	.06
> 80 years	-1.42	-3.50	.64	.18
Survey**	.01	-.01	.03	.23

#Differences between Males and Females, controlled for age.

*Compared with reference age group of 15-34 years.

**Change for over time controlled for age.

Table 5: Quality of Life and Psychosocial characteristics

Random effects GLS Regression* (Controlled for age)

Denial and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	-1.0	-5.1	3.1	.63
MCS	2.7	-2.0	7.5	.26
TOTAL MAQLQ-M	-.34	-.77	.08	.12

*Dichotomous variable of Denial score <3=0; >3=1, (scale range 0-5) (71)

Autonomy and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	-.62	-3.2	2.0	.64
MCS	2.8	-.15	5.7	.06
TOTAL MAQLQ-M	-.07	-.36	.22	.62

*Dichotomous variable of Total Autonomy <3=0; >3=1, (scale range 0-5)

Satisfaction with illness / Positive evaluations and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	.32	-3.4	4.0	.87
MCS	7.6	3.7	11.6	.000
TOTAL MAQLQ-M	.16	-.16	.49	.33

*Dichotomous variable of Illness satisfaction <3.99=0; >4=1 (92)

Table 5: Quality of Life and Psychosocial characteristics (Continued)

Health as a Value and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	-.21	-2.2	1.8	.84
MCS	-.04	-2.2	2.1	.97
TOTAL MAQLQ-M	-.02	-.18	.15	.85

*Dichotomous variable of Value Health <3.99=0; >4=1 (137)

Socially desirable responses and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	-1.5	-3.8	.76	.19
MCS	.89	-1.5	3.3	.47
TOTAL MAQLQ-M	-.06	-.26	.13	.54

*Dichotomous variable of Socially desirable responses

Social support and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	2.2	-.08	4.5	.058
MCS	-1.6	-4.6	1.4	.29
TOTAL MAQLQ-M	-.08	.36	.20	.59

*High score = less social support, and controlled for hospital

Avoidance Coping and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	12.5	7.7	17.2	.000
MCS	13.7	8.9	18.5	.000
TOTAL MAQLQ-M	1.5	1.2	1.8	.000

*Dichotomous variable of Avoidance (high score = less avoidance) (104)

Table 5: Quality of Life and Psychosocial characteristics (Continued)

Active Coping and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	5.6	.60	10.7	.028
MCS	-.81	-6.1	4.4	.76
TOTAL MAQLQ-M	.49	.17	.80	.002

*Dichotomous variable of Active coping <3.99=0; >4=1 (104)

Self-efficacy / Confidence and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	-1.7	-3.9	.43	.12
MCS	-3.9	-6.1	-1.6	.001
TOTAL MAQLQ-M	-.35	-.54	-.17	.000

*Dichotomous variable of Confidence (high score = less confidence)

Financial difficulties and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	4.8	2.7	6.8	.000
MCS	5.9	3.6	8.2	.000
TOTAL MAQLQ-M	.44	.26	.62	.000

*Variable of "Have you had any financial difficulties in the past 12 months?": 'Yes v No'.

Costs delayed care and Quality of life

	Coeff.	95% Conf.	Interval	p
PCS	2.7	.46	5.0	.018
MCS	4.5	1.8	7.2	.001
TOTAL MAQLQ-M	.56	.34	.77	.000

*Dichotomous variable of "Have concerns about costs caused you to delay seeking care for your asthma?": 'Yes v No'.

Table 6: Multivariate models of Quality of Life

Random effects GLS Regression (Controlled for Age)

PCS

Adjusted $R^2 = 0.69$ $R = 0.86$

Variable	Coeff.	95% Conf.	Interval	p
Avoidance	5.7	2.8	10.9	.001
Active	6.3	1.9	10.5	.004
Financial Diff.	3.9	.49	7.3	.025
Costs Delay	2.7	-1.3	6.7	.18
Rate Severity	4.2	1.0	7.9	.016
FEV_1*	-3.4	-6.1	-.81	.020
Reliever use	2.7	.01	5.5	.050

*FEV_1 coded as dichotomous variable with cut-point at 60% of predicted value

MCS

Adjusted $R^2 = 0.54$ $R = 0.76$

Variable	Coeff.	95% Conf.	Interval	p
Avoidance	8.0	2.1	13.9	.009
Financial Diff.	4.9	1.2	8.6	.009
Satis. Illness	2.9	1.0	4.8	.003
Rate severity	2.1	.52	3.8	.029
Reliever use	2.3	.04	4.8	.048

Table 6: Multivariate models of Quality of Life (continued)

Random effects GLS Regression (Controlled for Age)

TOTAL MAQLQ-M

Adjusted $R^2 = 0.69$ $R = 0.87$

Variable	Coeff.	95% Conf.	Interval	p
Avoidance	1.17	.75	1.61	.000
Active	.38	-.05	.80	.08
Financial Diff.	.44	.13	.76	.006
Costs Delay	.58	.18	.99	.004
Self-efficacy	-.19	-.53	.14	.25
Rate Severity	.64	.39	.90	.001
FEV_1	.33	.13	.53	.015

*FEV_1 coded as dichotomous variable with cut-point at 60% of predicted value

Table 7

Correlations with Change scores in TOTAL MAQLQ-M and disease measures

(n=232)

Pearson product moment correlation

	R	95% CI	p-value
Avoidance	.49	.36, .56	.000
Active	.08	-.10, .29	.31
Confidence	.20	.06, .33	.03
Costs Delay	.27	.09, .43	.002
Gross Income	-.15	-.28, -.01	.049
Financial Diffic.	.16	.01, .29	.05
Satis. Illness	.10	-.06, .25	.40
Δ Total Symptoms	.46	.36, .56	.000
Δ Self-Rating	.48	.39, .58	.000
Δ FEV_1 (% predicted)	.19	.03, .39	.038

Table 8: Multivariate analysis of change scores in HRQL.

(n=232)

Random effects GLS regression (controlled for age).

TOTAL MAQLQ-M

	Coefficient	95% Confid.	Interval	p
Avoidance	1.2	.8	1.6	.000
Costs delay	.46	.2	.7	.000
Finan. Diffic.	.25	-.04	.46	.02
Self-rating	.30	-.03	.48	.03

PCS

	Coefficient	95% Confid.	Interval	p
Avoidance	5.5	1.4	9.6	.001
Costs delay	2.2	-.54	4.9	.12
Finan. Diffic.	4.4	2.0	6.9	.002
Self-rating	2.3	-0.82	6.5	.11

Table 9

Change in MAQLQ-M over 12 months, by various patient characteristics:

(n= 232)

Avoidance Coping Style

Mean score Δ MAQLQ-M	Very High**	95% CI	High*	95% CI	Low+	95% CI
Δ Breathless	-.59	-1.4, +.30	-.10#	-.61, +.41	+.29##	-.05, +.64
Δ Mood	-.67	-1.5, +.17	-.34#	-.75, +.07	+.46##	+.20, +.71
Δ Social	-.82	-2.1, +.41	-.47#	-1.03, +.1	+.22##	-.02, +.46
Δ Concerns	-.71	-1.7, +.32	-.28#	-.74, +.18	+.27##	+.04, +.50
Δ Total	-.72	-1.7, +.27	-.27#	-.74, +.20	+.24##	+.04, +.46

** Very high avoidance coping = Avoidance scores <3 (n = 42) (see text)

* Higher avoidance coping = Lower tertile of avoidance scores (n=98)

+ Lower avoidance coping = Upper tertile of avoidance scores (n=97)

# p< .01, for comparison high and low avoidance coping

p< .001, for comparison very high and low avoidance coping.

Concerns about Costs delay seeking care for asthma.

Mean score Δ MAQLQ-Q	Yes (n= 150)	95% CI	No (n= 102)	95% CI	p-value
Δ Breathless	+.13	-.10, +.36	+.71	+.15, +1.3	.002
Δ Mood	+.01	-.20, +.23	+.33	-.09, +.75	.036
Δ Social	-.09	-.33, +.15	+.37	-.18, +.93	.011
Δ Concerns	-.01	-.21, +.20	+.36	-.10, +.82	.017
Δ Total	+.01	-.19, +.19	+.47	+.01, +.92	.002

Table 9 (continued)

Financial difficulties over the past 12 months

Mean score Δ MAQLQ-M	Yes (n= 129)	95% CI	No (n= 123)	95% CI
Δ Breathless	+.12	-.19, +.42	+.37	+.05, +.69
Δ Mood	-.17	-.41, +.07	+.36**	+.07, +.64
Δ Social	-.12	-.42, +.17	+.15	-.19, +.48
Δ Concerns	-.04	-.27, +.19	+.18	-.13, +.49
Δ Total	+.01	-.23, +.24	+.19	-.08, +.47

**p= .0005

Confidence / Self-efficacy in ability to manage asthma.

Mean score Δ	Low Confidence**	95% CI	High Confidence*	95% CI
Δ Breathless	-.12	-.49, +.25	+.44#	+.01, +.86
Δ Mood	-.12	-.47, +.23	+.13	-.18, +.44
Δ Social	-.19	-.63, +.25	+.05	-.32, +.42
Δ Concerns	-.02	-.38, +.34	+.09	-.26, +.44
Δ Total	-.11	-.44, +.22	+.18	-.15, +.51

#p= .009

*Upper tertile of confidence scores **Lower tertile of confidence scores

Active coping style.

Mean score Δ	Low Active**	95% CI	High Active*	95% CI
Δ Breathless	+.13	-.18, +.44	+.33	-.10, +.76
Δ Mood	+.20	-.14, +.53	+.02	-.31, +.35
Δ Social	-.07	-.50, +.36	+.03	-.36, +.41
Δ Concerns	+.01	-.33, +.36	+.01	-.34, +.37
Δ Total	+.02	-.33, +.36	+.10	-.24, +.44

**Lower tertile / *Upper tertile, of active coping style scores

Table 10: Determinants of Frequency of Reliever (bronchodilator) use.

Multiple Linear Regression (Controlled for age).

Adjusted $R^2 = 0.59$ $R = 0.79$

	Beta	SE Beta	B	SE B	p-value
Rate severity	-.58	.11	-.70	.14	.00005
Total MAQLQ-M	-.52	.17	-.55	.14	.0001
Avoidance	.53	.15	.50	.15	.0003
Active	-.15	.10	-.14	.09	.15
Self-efficacy	.41	.09	.51	.27	.0026

Table 11: Determinants of Self-reported treatment adherence.

Multiple Linear Regression (Controlled for age).

Adjusted $R^2 = 0.42$ $R = 0.68$

	Beta	SE Beta	B	SE B	p-value
Soc. Desirable*	.17	.07	.12	.05	.027
Avoidance	.21	.08	.21	.08	.011
Active	.23	.08	.19	.07	.006
SE concerns^{+}	.29	.08	.31	.08	.0001
Take prescribed**	.30	.08	.43	.11	.0001
Social support	.15	.07	.10	.05	.046

*Socially desirable response tendency

**Whether person takes medications as prescribed by doctor (self-report)

$^{+}$Concerns about medication side-effects prevent person taking medication

Chapter 6

Interpretation of changes in health-related quality of life scores.

Introduction

The clinical relevance of changes in scores on health-related quality of life (HRQL) instruments may be difficult to interpret. (1) Interpreting the literature requires distinguishing between statistical and clinical significance. (2) In particular, when therapy is not curative but designed to be ameliorative as it is in asthma, it is important to know whether a small improvement or deterioration in symptoms or function is important or trivial from the patients' perspective.

A large body of literature exists examining the methods for analysis to obtain the statistical significance of changes in scores, but less has been published looking at the concept of clinical significance. Pauker and Kassiser have suggested using decision analysis to locate where the magnitude of a clinical benefit offsets the attendant risks and costs. (3) Others have asked patients to evaluate their health relative to others to determine a threshold of clinical difference. (2) The approaches used by these studies have tended to conflate discrimination between patients with responsiveness to change. This may not be a valid assumption. (4,5) Jaeschke et al have defined the 'minimal clinically important difference' (MCID), as 'the smallest difference in a score, in a domain of interest which patients perceive as beneficial and which would mandate,..... a change in the patient's management". (6) These authors have suggested that measuring this is best achieved by anchoring the changes in quality of life scores to other clinical or subjective changes or results. (1,6) They argue that with experience clinicians develop an intuitive sense of the MCID for most clinical measures. However, as most HRQL measures remain research tools, the significance of changes requires some form of framework to assist interpretation.

A variety of methods have been proposed for estimating the minimally important difference in HRQL instruments. (7,8) Jones et al used physician-based criteria to estimate what difference on the St. George Respiratory Questionnaire would correspond to a clinically significant difference in health between two populations of patients. (9) Jaeschke and co-workers operationalised the MCID by looking at changes in a global-rating question over time and compared these with changes seen on a disease-specific questionnaire of COPD. (6) Subsequently, this approach has also been used to establish the MCID for the Juniper Asthma Quality of Life Questionnaire (AQLQ). (10) Using this method on a number of instruments scored with 7-point Likert scales, the McMaster group have found that a change in mean score of 0.5 may be considered the smallest difference a patient perceives as a significant change in either improvement or deterioration. (6,10,11) Barber and colleagues repeated this process on the Juniper AQLQ and found the MCID was not symmetric. Patients in their sample appeared to be more sensitive to deterioration than to improvement. They also found that generally the MCID was smaller in their sample than the Juniper group reported from their study. (12)

These instruments utilise 'informed' administration; that is, subjects are shown their previous responses prior to completion of the follow-up survey. This maybe useful for respondents to "anchor" their answers to the previous responses. However, it places somewhat of an organisational and administrative burden on investigators using these tools in follow-up trials or in clinical practice. In addition, these scales also use 'patient-specific' or 'personalised' items in the daily activities domain. Patients identify which most important activities should form the items for this domain. It remains unclear whether these features are a critical aspect of determining the MCID for all instruments using a 7-point Likert scale or not. The disadvantage of using patient-specific items is that comparing activity scores between patients is difficult as they refer to different activities. It is also difficult to compare different studies and different populations. (13) Further, it may increase the signal-to-noise ratio in group comparisons. (14) Patients are also required to

identify activities they will be performing for the duration of the study follow-up period. With the Juniper AQLQ some of the suggested possible activities include such things as "shovelling snow". (15) Items such as these present not only difficulties with longitudinal follow-up in different seasons of the year, but also cross-cultural and trans-national problems with administration and population comparisons, particularly in a southern hemisphere setting. It would therefore be useful to ascertain what is the MCID for an instrument using a 7-point Likert scoring scale, which has fixed items and does not require informed administration. It is also important in interpreting HRQL changes to determine if changes are similar across domains and if the MCID is symmetrical; ie whether the significance of deteriorations are the same as improvements.

None of the other asthma disease-specific questionnaires, nor the SF-36, has been subjected to this type of analysis. The method of Jaeschke et al (6) was used in an attempt to ascertain the MCID of the modified Marks AQLQ (MAQLQ-M), and the SF-36 Health Survey Physical (PCS) and Mental Component Summaries (MCS). (16,17). It was hypothesised that the MCID for the MAQLQ-M would be similar to that found for other scales using the 7-point Likert scales, ie around 0.5. It was also expected that the disease-specific questionnaire would be more sensitive to change than the generic SF-36 survey.

Methods

Survey methodology is described in Chapter 3, "Methods". Questionnaires included the MAQLQ-M and the MOS Short-Form 36 (SF-36) Health Survey (34-36), along with the battery of measures for psycho-social, clinical and demographic variables. These were administered at 3 monthly intervals. The psychosocial measures are summarised in Table 1. The HRQL and

clinical measures are shown in the Appendix, pages 355, 359-362 and pages 349-354

At the second survey period, each respondent was asked to make global ratings of changes in their asthma generally. Subjects were asked,

"Overall, has their been any change in your asthma?

Has your asthma been:

1. Worse
2. About the same
3. Better"

If patients stated they were worse, they were asked how much worse on a seven-point scale:-

1. Almost the same, hardly any worse at all
2. A little worse
3. Somewhat worse
4. Moderately worse
5. A good deal worse
6. A great deal worse
7. A very great deal worse

If subjects indicated they were better, similar response options (with substitution of 'better' for 'worse'), were offered. This produced a 15 point global rating scale for changes, ranging from -7 (maximum deterioration), to 0 (no change), and +7 (maximum improvement). In order to provide clinical meaning to the magnitude of change the methods of Juniper et al were used. (10) Patients who scored 0, +1, or –1 on the Global Rating of Change instrument were classified unchanged. Changes from -2 to -3 and +2 to +3 were taken to represent small changes in function, -5 and -4, and +4 and +5 were considered to represent moderate changes, and -6 and -7, and +6 and +7 were classified as having large change. Thus, the MCID would be represented by changes in the HRQL questionnaire scores associated with

global ratings of -3 to -2 and +2 to +3. The MCID for improvement and for deterioration are reported.

The designation of what ratings from the Global Rating Scale suggest a small but important change is necessarily subjective and arbitrary. Jaeschke et al originally classified changes of ± 1-3 as a small but significant change. (6) Subsequently, Juniper and colleagues modified this by classifying respondents whose global score was ± 1 as unchanged. (10) It is this modified approach that is followed here; thus those who responded as "almost the same, hardly any better/worse at all", are classified as fundamentally unchanged.

Change scores are expressed as mean scores for each domain, which allows comparisons between domains. If there was a dependency between the observations within a patient, and some subjects were lost to follow-up, biases may be introduced by including subjects with multiple observations in the analysis that may have greater influence on the comparisons than those with only a single observation. To avoid this problem, only a single observation from each patient was used in calculating the results. This left 234 observations available for analysis, comparing changes from baseline and at 3 months follow-up. Unlike the Juniper AQLQ, respondents are not shown their previous responses when completing the MAQLQ-M. In order to maximise independence of response, the HRQL questionnaires were situated at the beginning of the survey material sent to patients, and the global rating items came at the end of the stapled survey document. Scores for the MAQLQ-M for each survey period are reported in Chapter 4, 'Validity of two health-related quality of life instruments in asthma'.

To test the robustness of the findings two subgroup analyses of those who reported changes on global ratings were performed. To determine whether the threshold of clinically significant change might differ depending on the patients' age, respondents were divided into two groups. Those below 40 years were classified as young, those between 40 and 65 years as middle-

aged, and those over 65 years as elderly. Similarly, to determine whether the MCID threshold depended on level of quality of life, respondents were divided into tertiles (thirds) depending on MAQLQ-M scores. (2) In each analysis, the MCID thresholds were estimated and the differences evaluated using ANOVA.

Responsiveness and Precision.

Responsiveness evaluates an instrument's ability to detect small changes in quality of life. This relates to the magnitude of change, and to the reproducibility of the questionnaire in stable subjects. (7,20,21) A Responsiveness Index (RI) proposed by Guyatt uses the ratio of the minimum clinically important change to the between subject variability of difference scores in stable subjects. (7) An alternative method proposes using the mean observed change in subjects known to have improved as the numerator. (20,21) This measure of responsiveness is dimensionless and is related to an effect size. (21,22) The magnitude of the responsiveness index signifies how useful the measure is in distinguishing subjects who have improved (or deteriorated) from stable subjects. (20) This relates to the variance of change in stable subjects (Table 5). Confidence intervals, which do not include zero, indicate significant responsiveness.

Responsiveness indices were calculated using both the methods of Guyatt et al and Tuley et al. (7,21) These were estimated by, 1) using the MCID as calculated above as the numerator , and 2) by using the mean change in HRQL scores in subjects who had a more than a 20% change in symptom scores or in pre-bronchodilator FEV_1 between baseline and follow-up, as the numerator.

The issue of responsiveness also relates to the measurement precision of the instrument in both cross-sectional studies and for longitudinal monitoring. For

cross-sectional measurement at a single point in time, internal consistency reliability is often used. (23) These values, and those of test-retest reliability, for the MAQLQ-M and SF-36 have been reported in Chapter 4, 'Validity of two health-related quality of life instruments in asthma'. This showed reliabilities that exceeded or were within the ranges of recommended standards. (23) The standard error of measurement (SEM) is the standard deviation of an individual score and it is the most useful reliability estimate for individual-level applications. The SEM reflects both reliability and variance, as defined by standard deviation x $\sqrt{}$(1 – reliability). (23) The 95% confidence interval can be calculated to gauge the certainty of the score. The 95% CI is an index of the random variation expected if an individual were tested repeatedly. From Chapter 4, the 95% CI of the SEM for the TOTAL survey was 0.4, for the BREATHLESSNESS and SOCIAL scales it was in excess of 0.5, and for the MOOD and CONCERNS sub-scales the values were >0.7. Values for the SF-36 PCS and MCS were 6.2 and 8.0, respectively.

This concept can be applied to test-retest reliability estimates. The 95% CI estimates of the SEM can be used to gauge the likelihood that a difference between two scores for an individual is attributable to random error rather true change. If the difference between the two scores lies between the 95% CI then it is likely the observed change is random error. (23) This has been defined as the Reliable Change Index. (24) The implication of this is that to be confident that the estimated average MCID represented true change its value should lie outside the SEM for test-retest reliability. Test-retest reliability, estimated using intra-class correlation coefficients as described by Deyo and colleagues, are reported in Table 4. (25) For the TOTAL score the 95% CI of the SEM was 0.62, for BREATHLESSNESS and SOCIAL it was around 0.7, and for the other two scales it was 0.8. For the PCS this value was 7.2, and 9.8 for the MCS.

An alternative analytic strategy for evaluating constructs of change is the receiver operating characteristic (ROC) curve. (4,26) The ROC curve plots sensitivity against specificity. Sensitivity is defined as the number of patients

correctly identified (by a given measure) as undergoing an important change divided by all patients who truly did undergo an important change. Specificity refers to the number of patients who correctly identified (by a given measure) as not undergoing an important change divided by all patients who truly did not undergo an important change. The relative value of various cut-off points can be compared to evaluate which is the best overall cut-off point. (17,27) Hanley and McNeill have reported *z*-scores can be used to compare the differences in ROC curve areas. (28) These relate the differences to the standard errors of the differences in areas. The TOTAL MAQLQ-M was compared with the PCS of the SF-36 using this method.

Results

From the initial sample of 293, some 254 respondents completed the 3-month surveys, a retention rate of 80%. There was a predominance of females with 33% of subjects being male. Mean age of the population was 42.3 years, with a median age of 41 years, and a range of 15 to 85 years. Fifty-five percent were recruited from The Queen Elizabeth Hospital, the remainder from the Lyell McEwin Health Service. Comparison of the scores at baseline for those with and without 3-month follow-up indicated no statistically significant differences in scores between these two groups (p= .66), and standard deviations and score ranges suggested similar distributions of scores. There were no statistically significant differences in the two groups with and without 3-month follow-up when compared for age, gender, baseline symptoms, or household income.

Estimates of the threshold of clinical importance.

Results are shown in Tables 1. Each table deals with a domain of the MAQLQ-M and the PCS of the SF-36, and indicates the numbers in each category of the global rating item and the corresponding mean change score for the domain of the questionnaire. Overall, the data indicates that the MAQLQ-M and the SF-36 PCS are capable of detecting both improvement

and deterioration in patients with asthma. The domain score averages associated with the 'no change' were all close to zero as expected. The difference between the 'no change' average and the 'minimally improved' average were slightly greater than the differences between 'no change' and the 'minimally worse' average. That is, the distribution of changes was not absolutely symmetric. On average, patients were more sensitive to deterioration than improvement in their asthma across all domains. Subjects required more change by about 0.1 on the MAQLQ-M to report global improvements in that domain, than for deterioration. The exception was the SOCIAL sub-scale, where the 'minimally improved' average was less than the 'minimally worse' average. However, the two estimates were not statistically significantly different from each other, therefore average MCID values are also presented. Similarly, for the PCS, a larger change in scores was needed to signify improvement than deterioration.

The mean change per domain corresponding to the MCID for most of the sub-scales was around 0.5 for deterioration and 0.6 for improvement. A larger improvement in the CONCERNS sub-scale was needed before patients noted a perceptible change in this area of their life. Due to sample size issues the numbers for moderate and large effect have been combined. A change of around 1.0 signifies an at least moderate alteration in quality of life. For the PCS a change of around 5 corresponded to the MCID, and above 8 to signify a moderate or large change in HRQL. The score for the unchanged group was around 3, a relatively larger change in terms of the group standard deviation on the SF-36, than the unchanged group scored on the MAQLQ-M.

It was then possible to apply this approach to evaluate the changes in MAQLQ-M between baseline and 3 months for each of the two hospitals (TQEH and LMHS). (29) Table 3 shows that there was a heterogenous experience of asthma quality of life for the subjects in the study over the 3-month period. The proportions of patients who had a clinically significant change in some aspect of quality of life during this period ranged from 51% to

65%. Large changes in quality of life were seen in 14% to 18% of subjects over the 3 months.

Responsiveness

Responsiveness indices for the MAQLQ-M were calculated using both the methods of Guyatt et al and Tuley et al (Table 5). (7,21) The TOTAL score and all of the sub-scales demonstrated the ability to distinguish between the two groups of patients according to both definitions of change. The lower values of the RI for the clinical measures of symptoms and FEV_1 derive from the much wider variation in scores in patients who did not reach the criteria for change on the clinical measures. In other words, patients reported a relatively wide range of score changes on the HRQL without a corresponding change on the clinical measures. Given the necessarily arbitrary nature of the judgements made to establish the MCID, and also those used to determine significant improvements in lung function and symptoms, sensitivity analyses were performed for different values of the MCID (Table 6). The responsiveness index remained significant if the MCID score change was varied between 0.3 and 1.5.

A summary of the performance of the MAQLQ-M and the SF-36 at various cut-points in assessing the MCID using ROC curve analysis is shown in Table 7. The best all-round cut-off for the TOTAL MAQLQ-M Q is 0.6, achieving a sensitivity of 76.2% and a specificity of 75.6%, with an area under the ROC curve of 0.76. For the PCS of the SF-36 the optimum is 6.0, which achieves an area under the ROC curve of 0.66, and a sensitivity of 59.1% and 72.3%, respectively. Using the method of Hanley and McNeill, the differences in ROC curve areas for the two measures were compared, and a significant difference was found (p=0.036).

Tests of robustness of the MCID

To evaluate the robustness of the MCID estimates for the MAQLQ-M, analyses of subgroups classified by age and quality of life level were performed (Table 2). The results demonstrated that thresholds for younger and older patients were not different. The MCID for subjects with moderate quality of life (the middle third of the MAQLQ-M distribution) was lower than for either of the other two groups. In turn, those who reported better quality of life (top third) were more sensitive to change than patients with poor quality of life (bottom third). The difference between the middle third and the lowest tertile group was statistically significant.

Discussion

The results demonstrated that when using a 7-point scale for response options in the MAQLQ-M, a within-subject change of approximately 0.6 represents a minimal important difference. A change of about 1.0 can be considered at least a moderate change in quality of life. For the PCS a change of around 5 corresponded to the MCID. From the values of the Reliable Change Index for the TOTAL MAQLQ-M scale, this MCID value corresponds to the 95% CI of the SEM. Hence a change of this magnitude can be with some confidence be expected to be a real change in quality of life. For the PCS of the SF-36 a score of over 7 is required before we can be confident a real change has occurred. The results for the MAQLQ-M are remarkably similar to those obtained by Juniper and colleagues for their AQLQ, and for a number of other scales that also use a 7-point response scale. (6,10,11) As these authors have pointed out this observation may mean that those interpreting results of quality of life studies will be able to apply the same standards for judging the magnitude of effects across a wide variety of instruments. (10) The potential significance of the above findings lies in the fact that the MAQLQ-M was developed in a completely different fashion to the Canadian questionnaire, using factor analysis rather the 'impact' method used by Juniper and workers. It also does not require

'informed' administration with subjects shown their previous responses, nor is the domain relating to functional status 'personalised', with patients determining the content of the items. (15,16) The absence of these features may have advantages in reducing the administrative burden for both users and patients and in allowing comparisons between populations. As discussed in Chapter 3, 'Methods', considerable difficulty was experienced in the use of the personalised 'Activities' domain of the McMaster AQLQ in the pilot period of the study, such that that instrument was abandoned and replaced with the MAQLQ-M. The demonstration that the MAQLQ-M is sensitive and responsive to small changes in quality of life, combined with its psychometric validity and its potential for cross-population comparisons, means it is a useful tool for asthma outcome studies in a wide variety of settings. The discordance between the MCID and the Reliable Change Index for the PCS, combined with the larger variance in stable subjects suggests that the SF-36 component summaries are less powerful instruments for assessing change in asthma patients' quality of life. This was also supported by the comparisons of the area under the ROC curves, as discussed below.

The results were reasonably consistent across the sub-scales of the MAQLQ-M. As some interventions may be designed to affect a particular aspect of quality of life, a change of about 0.6 – 0.7 within an individual domain signifies an important change in that aspect of quality of life. Awareness of the MCID is also helpful when data appear as confidence intervals. For example, a study showing a small mean difference with an intervention, may also have a wide variability, hence the mean value will conceal the significant changes some patients have experienced. This can be seen with the study population here, where a majority of subjects experienced significant changes in some aspects of quality of life, but the mean scores did not alter over 3 months. Guyatt et al have described how a superficial examination of mean differences can lead to erroneous conclusions. (29) They point out that the notion of taking a continuous variable, specifying a threshold and examining the proportions of patients who reach that threshold is not new. However, by anchoring the threshold difference to the patient-determined minimal clinically

important difference they demonstrate how the method can be used to generate the number needed to treat for a single patient to benefit in both crossover and parallel group trials. (29) Thus the knowledge of the MCID for this instrument may have major implications when considering the effects of a treatment, particularly for the cost-effectiveness of any intervention.

The ability to detect deterioration is separate from the ability to detect improvement, and needs to be established rather than assumed. (20) This study has shown the MAQLQ-M was sensitive to deterioration over a relatively short time period in asthma patients, most of whom had moderate to severe disease. This property had not been established for the MAQLQ-M previously. (20) When used in the setting of an intervention trial, where it is assumed most patients will improve, this quality is not as important as in the non-research clinic situation. If the MAQLQ-M is being used to monitor patients in the routine clinic setting, the ability to detect a negative change is as important as the capability to detect improvements. Whether this remains true with long-term follow-up over many years still remains to be determined.

The threshold for the MCID is not an exact number. (2) The data suggest a plausible range within which the MCID probably falls. (6) The global rating ordinal scale was the criterion standard of change. The reason for electing to dichotomise this scale at a "minimally perceived" change point is that clinical decisions are often dichotomous in nature. The clinical question often is, has the patient's health status changed or not, so that a change in treatment is or isn't needed. (30) The choice of cut point is often arbitrary, and the choice is made on clinical judgement. (10) Stratford and colleagues has demonstrated that in comparing two measures, the results for the RI can be affected by the choice of the cut point for the MCID. (30) While this may be a limitation of this test, it may also reflect the problem of assuming interval qualities of both the HRQL instrument and the global rating of change scale. Different instruments may well behave differently in their characteristics when measuring health status at different levels of impairment. (31) It is worth noting that the studies establishing the MCID of the Juniper AQLQ used small

sample sizes (n<50), and were generally patients classified as mild to moderate in severity. For example, the sample for the original report of this tool excluded any subjects taking greater than 800 micrograms/day of inhaled corticosteroids. (32) The standard deviations of the scale scores in these studies were small, whilst in other studies the cross-sectional and test-retest reliability coefficients of this instrument have often been much lower than those found in this study. (12,33) Thus in a sample with a greater standard deviation than the original paper from the McMaster group, the statistical reliability of the MCID values they found would be considerably reduced.

The subgroup analyses of different levels of quality of life illustrate this problem of quality of life measurement non-linearity. The MCID was different for all three tertiles of the HRQL distribution. Those in the middle third reported a smaller MCID than subjects at either extreme of the HRQL scale. This may reflect a real clinical phenomenon; patients with either poor or good quality of life may require a larger alteration in their clinical status to perceive a change. However, given the countless ways in which a score is achieved in HRQL measures, this may at least in part reflect the structure of the scales. McHorney has noted that in the development of instruments acceptable standards of validity and reliability with few items are best achieved by selecting items that are fairly homogeneous. Thus, selected items are often in the middle range of item difficulty. (34) Stucki et al found that patients with worse initial health required larger numerical gains on the Physical Function scale of the SF-36 than patients with better initial health to perceive some improvement in function. (31) Although interpretation of their data was limited by the sample size, they also found that the middle tertile needed less numerical improvement in scores in order to notice an improvement. The use of item response theory as an alternative scoring method for HRQL instruments that can simplify analysis of change scores is discussed in Chapter 7.

How survey respondents interpret the possible response options may also be important in how those individuals score changes and what these mean. It is

possible people moving from "none of the time" to "hardly any of the time" (or vice versa) for a problem perceive that there has been minimal change in overall health status. However, a threshold effect may operate, whereby a particular problem may not cause a perceptible limitation in overall health status until it reaches a certain level, and a change in either direction around that level may cause a definite alteration in perceived status beyond the apparent measured change. (35) Alternatively, those with very poor health may see little real changes in their lives despite small alterations in some problems. Hence, they may require things to improve to a certain level that accords with their expectations of health before a perceptible improvement is noted.

Other factors may be involved as well. Regression to the mean will tend to be in opposite directions for patients whose baseline health is excellent and for those whose baseline health is poor. (35) Thus for patients whose true health is declining, the measured change for patients in better health tends to systematically overestimate the true change, whilst the opposite occurs at the other end of the scale. The size of this effect is difficult to determine. Another limitation is the use of a single global rating of change question to compare with the change in health status score. It is possible that components of health were altered differentially at different levels of health status leading to the discrepancies seen between groups.

It is possible to overstate the importance of the finding of non-linearity, however. The difference in MCID for each tertile was only 0.1-0.2 on average across all of the sub-scales. The major implication of the variation with baseline scores may be for sample size and power calculations for clinical trials. Sample size depends on the magnitude of the difference investigators consider clinically important and are not willing to risk failing to detect. (6) In order to adequately interpret HRQL changes analyses should be conducted based on baseline status. It would therefore be necessary to ensure that the sample size is adequate to provide sufficient power to allow interpretation of effects, or to ensure that the samples are sufficiently homogeneous with

regard to quality of life status so that an average MCID is meaningful. Caution should be used when interpreting changes in health status between groups if there are differences between the frequency distribution of baseline health between the groups. Future work could explore the issue of whether a scoring system weighted by individual preferences would have advantages in sensitivity and reliability to detect changes in disability. (36)

Tuley et al have considered the issue of the power of a test of a treatment effect and its relationship to the responsiveness index (RI). (21) They give an example of a method for comparing the RI of two different instruments. In all cases the values for the responsiveness index obtained here were greater than those reported by Marks et al in their original paper describing the AQLQ-M. (20) The RI reported here for a wide range of the MCID shows that the MAQLQ-M with the 7-point response scale is highly responsive to change. To examine whether it is more responsive than the original questionnaire requires both instruments to be administered simultaneously to the same population, and the MCID to also be determined in this process using the global rating scale. To compare the responsiveness of the two instruments it is necessary to know the correlations of the differences obtained with the two instruments in the same population in order to compute the estimated covariance. (21). This would allow determination of whether use of one or the other would result in greater power, with consequent implications for sample size calculations in a trial setting. (21) This data is not available. As the objective of this study was to establish the validity, reliability and responsiveness of the modified 7-point scale, the comparison trial is an area for future work.

Using the ROC data for the two instruments, the TOTAL MAQLQ-M score and the PCS of the SF-36, it was possible to compare which is more effective at assessing change. (30) Using the optimum cut-points for each measure, the TOTAL MAQLQ-M was a more powerful tool for change measurement. The SF-36 performed reasonably well, however it was the increased variability of scores in subjects assessed as stable by global rating or on

clinical grounds, that was chiefly responsible for the lower area under the ROC curve compared with the MAQLQ-M. The optimum value for the MAQLQ-M also corresponded to the MCID estimated from the mean score of those with the minimum global change. This was also close to the 95% confidence intervals of the SEM, indicating a change of this magnitude is less likely to be due to chance. This result is consistent with the contention that is often asserted but has seldom actually been established with data, that disease-targeted instruments are more sensitive to change than generic measures. (37-40)

Between-patient variability in the MCID is probably true for physiological measures as well as quality of life instruments. (6) Comparison of the MCID as assessed by the global rating scale with changes in symptom scores and lung function revealed a wide variability in confidence intervals of the threshold for MCID for each reference measure. That is, there was a large range of symptom and lung function changes across which patients perceived a change in their quality of life. This again points out the limited degree to which conventional clinical measures correspond to the perception of quality of life by patients. (20) Some authors argue that given that the wide variation in the perception of airway narrowing seen in asthma patients' (41), and the heterogeneity of patients in terms of circumstances and temperament, a moderate correlation between HRQL and physiological measures is all that should be expected. (42) The implication is that quality of life measures add complementary information to conventional clinical outcomes. Another issue in measuring health status over time is that within-patient variability on a measure in patients whose health is stable, often increases as the duration between assessments increases. (30) The RI will tend to be lower in a study such as this one where some, but not most patients, had a clinically significant change with time, compared with a study where most subjects can be expected to have changed. (30) Related to this is the finding that patients can change how they evaluate their quality of life over time. (43) This is understood to represent a psychological adaptation or a 'response shift', that can occur in patients with chronic diseases. (44) To this extent reported

changes in quality of life need not necessarily derive from actual changes in health. (43) While this is unlikely to be a factor in this study measuring change over a 3-month period, it should be kept in mind when long-term follow-up studies are planned.

Criticism can be made of the nature of the sample, deriving only from patients managed in hospital clinics. Patient recruitment is seldom truly random. (45) The relevance of determining the MCID on hospital-clinic patients is two-fold. Firstly, these are patients who by and large suffer greater morbidity and chronic disability, and have higher cost burdens imposed on themselves and on the community, than other groups of patients. (46-48) For these reasons interventions are often targeted specifically at these patients. Knowledge of what these individuals' regard as a significant improvement is important for determining the sample size of the study and the cost-effectiveness of the intervention. The applicability of the MCID determined in this study to a broader asthmatic population remains unknown, and future work is necessary to see if differences are seen in other populations, such as community samples of persons with asthma.

There is also the issue of the validity of using patient assessment of change as the criterion standard, as it means that this is not independent of the functional status measure being assessed. (30) There is no standard external criterion for patient improvement or deterioration. (36) Some authors have also suggested that patients have difficulty recalling the original state that on which they are basing their estimate of change. (49) As discussed above, this is a complex methodological issue. The correlations with other clinical measures found in Chapter 4 suggests that the survey changes at least are related to clinical changes. Furthermore, the similarity between the values obtained in this study and those from authors reporting with instruments using 'informed' administration also suggest recall is consistent. It is also interesting to note the comparatively good correlation between the assessment of 'general change' in asthma and changes in the MAQLQ-M, reported in Chapter 4.

As Barber and colleagues have shown with the Juniper AQLQ, the question used to anchor the overall rating of change in the disease needs to be taken into consideration so that the context of the meaningful change can be understood. (12) It would be an interesting area for future research to compare different wordings of the anchor question to ascertain whether the MCID for the MAQLQ-M and the SF-36 are affected.

Conclusion

In summary, the MCID for the MAQLQ-M and the SF-36 Physical Component Summary has been established in asthma patients recruited from hospital clinics. As hypothesised, the MCID for the MAQLQ-M was similar to that previously for those scales that use a 7-point Likert scale, despite respondents not being shown their previous answers. The MAQLQ-M has been shown to be a more responsive instrument than the SF-36 in this population. The results provide further evidence for optimism for the easy interpretation of quality of life measures. (10)

Table 1: Changes in HRQL anchored to global rating changes.

Change in TOTAL MAQLQ-M

Global category	N (n=254)	Mean change MAQLQ-M	95% CI of mean Δ
Worse (-4 : -7)	16	-.92	-.60, -1.30
Minimally worse (-2 : -3)	38	-.48	-.26, -.69
No change (-1, 0, +1)	110	+.10	-.05, +.22
Minimally better (+2:+3)	51	+.57	+.34, +.78
Better (+4 : +7)	19	+1.02	+.76, +1.30

Change in BREATHLESSNESS sub-scale (MAQLQ-M).

Global category	N (n=254)	Mean change MAQLQ-M	95% CI of mean Δ
Worse (-4 : -7)	16	-.88	-.56, -1.22
Minimally worse (-2 : -3)	38	-.39	-.18, -.67
No change (-1, 0, +1)	110	+.07	-.04, +.16
Minimally better (+2:+3)	51	+.46	+.20, +.68
Better (+4 : +7)	19	+.95	+.66, +1.26

Change in MOOD sub-scale (MAQLQ-M).

Global category	N (n=254)	Mean change MAQLQ-M	95% CI of mean Δ
Worse (-4 : -7)	16	-.81	-.50, -1.06
Minimally worse (-2 : -3)	38	-.37	-.19, -.60
No change (-1, 0, +1)	110	+.11	+.01, +.19
Minimally better (+2:+3)	51	+.61	+.45, +.75
Better (+4 : +7)	19	+.94	+.64, +1.38

Table 1: Changes in HRQL anchored to global rating changes. (cont'd)

Change in SOCIAL sub-scale (MAQLQ-M).

Global category	N (n=254)	Mean change MAQLQ-M	95% CI of mean Δ
Worse (-4 : -7)	16	-1.09	-.79, -1.41
Minimally worse (-2 : -3)	38	-.61	-.25, -.98
No change (-1, 0, +1)	110	-.05	-.18, +.10
Minimally better (+2:+3)	51	+.39	+.11, +.69
Better (+4 : +7)	19	+.87	+.59, +1.12

Change in CONCERNS sub-scale

Global category	N (n=254)	Mean change MAQLQ-M	95% CI of mean Δ
Worse (-4 : -7)	16	-.99	-.66, -1.31
Minimally worse (-2 : -3)	38	-.44	-.71, -.18
No change (-1, 0, +1)	110	+.11	-.04, +.22
Minimally better (+2:+3)	51	+.72	+.33, +1.06
Better (+4 : +7)	19	+1.22	+.97, +1.48

Change in Physical Component Summary (SF-36)

Global category	N (n=254)	Mean change PCS	95% CI of mean Δ
Worse (-4 : -7)	16	8.9	-5.7, -13.1
Minimally worse (-2 : -3)	38	4.4	-0.8, -8.3
No change (-1, 0, +1)	110	3.2	-2.1, +7.6
Minimally better (+2:+3)	51	4.9	+0.5, +9.2
Better (+4 : +7)	19	8.2	+4.0, +12.4

Table 2: Changes in TOTAL MAQLQ-M scores anchored to global rating changes, organised by patients' age and baseline health status.

Changes in MAQLQ-M by age groups.

Age group	**N (n=124)**	**Mean change MAQLQ-M** (better & worse combined)	**95% CI of mean Δ**
< 30 years	42	.46	.16, .74
30-55 years	45	.48	.18, .81
>55 years	37	.49	.17, .80

Change in MAQLQ-M by baseline health status.

Baseline (in tertiles)	**N (n=124)**	**Mean change MAQLQ-M** (better & worse combined)	**95% CI of mean Δ**
Lower third	41	.66*	.33, 95
Middle third	42	.41*	.18, .62
Higher third	41	.51	.24, .80

(*p= .0043 for mean of lower third versus middle third.)

Table 3: Proportion of patients reporting minimally significant changes in the MAQLQ-M:- by Hospital.

	All subjects			LMHS			TQEH		
	+	0	-	+	0	-	+	0	-
Total	.30	.47	.23	.27	.46	.27	.35	.48	.17
Breath	.36	.43	.21	.29	.46	.25	.43	.40	.17
Mood	.37	.35	.28	.35	.34	.31	.39	.35	.26
Social	.24	.46	.27	.25	.44	.31	.30	.49	.21
Concerns	.32	.43	.25	.30	.40	.30	.35	.58	.18

+ / - = Minimal clinically significant improvement / deterioration

0 = No perceptible change

Table 4: Longitudinal measurement precision:

Reliable Change Index**

HRQL variable	Reliability#	SEM	90% CI	95% CI*
Total	.92	.33	.54	.66
Breathlessness	.90	.37	.61	.74
Mood	.87	.43	.70	.86
Social	.92	.40	.66	.80
Concerns	.90	.42	.69	.84
PCS	.89	3.6	5.9	7.2
MCS	.84	4.9	8.0	9.8

** See text for definition.

Test-retest reliability, Intra-class correlation coefficient.

##90% CI equals 1.64 SEM

*95% CI equals 2 SEM

Table 5: Responsiveness of the MAQLQ-M.

	Responsiveness Index*			
	MCID 0.5	95% CI	MCID Clinical**	95% CI
Total	2.3	1.5, 3.2	1.70	0.7, 2.8
Breathless	2.0	1.1, 2.9	2.2	0.9, 3.4
Mood	1.5	0.8, 2.3	1.3	0.5, 2.1
Social	1.6	0.8, 2.5	1.8	1.0, 3.0
Concerns	1.5	0.5, 2.6	1.2	0.4, 1.9

*See text for definition.

**>20% Change in Symptoms or FEV_1.

Table 6: Sensitivity Analyses of the Responsiveness Index for various MCID scores of the MAQLQ-M.

(TOTAL MAQLQ-M)

MCID	Responsiveness Index	95% CI
0.3	1.9	1.2, 2.6
0.8	1.9	1.1, 2.7
1.0	2.2	1.3, 3.0
1.5	3.4	2.7, 4.1

Table 7: Performance of the MAQLQ-M and the SF-36 at various cut-points in assessing the MCID (n=254)

ROC analysis

Change in TOTAL MAQLQ-M Scale - Cut-points

	0.1	0.3	0.5	0.6	0.8	1.0
Sensitivity (%)	94.3	83.4	81.1	76.2	61.6	49.5
Specificity (%)	38.7	45.6	64.7	75.6	82.4	88.7
False positive rate (%)	61.3	54.4	18.9	25.4	17.6	11.3
False negative rate (%)	5.7	16.6	35.3	23.8	38.4	50.5
Area under ROC curve	0.66	0.65	0.73	0.76	0.72	0.69

Change in SF-36 PCS Scale - Cut-points

	1	3	5	6	8	10
Sensitivity (%)	79.5	70.2	55.1	59.1	51.6	40.1
Specificity (%)	38.3	53.6	69.2	72.3	78.3	82.3
False positive rate (%)	61.7	46.4	29.8	27.7	23.7	19.7
False negative rate (%)	20.5	29.8	42.9	40.9	51.4	52.9
Area under curve	0.59	0.62	0.62	0.66	0.65	0.61

Chapter 7

Item-response theory and Asthma quality of life scales.

Introduction

Authors have conceptualised the different domains of quality of life as representing unobservable, latent constructs of functioning and well being. (1) These unobservable constructs can then be measured by a collection of representative questions. Each item has some unknown, true relationship with the construct, but also has both systematic and random error components. A series of items measuring quality of life are often combined into a single composite variable, or scale. The composite scale has the advantages of parsimony, in allowing a single variable for use in statistical analysis, and stability, in that the collection of items provides a more reliable measure of quality of life than any of the individual constituent items. Classic psychometric theory assumes that a scale is unidimensional (measures only one thing, such as physical function) and that the items are a random sample of an infinite pool of potential items concerning that domain. (1,2)

In traditional test theory the quality of the individual items making up the test score may be evaluated in terms of several item characteristics. The discriminating power of an item is given by the item-total correlation (the point-biserial correlation coefficient) which is the correlation across all persons between the score for that item and the total scores (or the total scores excluding that particular item). The fit of an item to a scale is indicated by its factor loading, estimated as part of a factor analysis to test the unidimensionality of the scale. The quality of the test as a whole may be evaluated by measures of reliability and by discussing the validity.

However, many of the assumptions underlying the above traditional test measurement theory are being challenged. For example, the facility and

discriminating power of the items depend on the particular group of persons used for the evaluation (i.e. they are sample dependent). Factor analysis assumes variables at the interval level of measurement following normal distributions. Reliability measures based on procedures such as split halves or test-retest are essentially artificial. Total test scores produced by summing the values of the constituent items are bounded by their zero and maximum values, and therefore cannot form a scale at the interval level of measurement. The classic techniques for selecting items for inclusion in scales tend to favour items of intermediate difficulty. This in turn creates scales that discriminate most reliably near the middle of their ranges of measurement. (3) In a scale designed to measure a general population, most people fall near the middle in a normal distribution. However, for subjects who score at the extremes of a scale, where clinical interest is often greater, the scale may be less reliable. For these subjects, changes in summed scores may depend on their starting point on the scale, rather than their actual change on the underlying dimension of health. (4,5) Hence, scales may not be equidiscriminating across their range, and traditional test theory does not easily identify how far a scale falls from achieving an interval level of measurement. There is also no way other than scanning the data to measure the degree of inconsistency in the pattern of item responses by any given individual.

The aim of this study was to examine the scale properties of the modified MAQLQ-M and the SF-36 Physical Functioning and Mental Health scales using the partial credit method of item–response theory. Specifically, the hierarchical order and spacing of item calibrations will be shown; the unidimensionality of the scales will be examined; the issue of transforming the raw scores into IRT-interval measures and the usefulness of using IRT-measures for the interpretation of individual quality of life will be explored. The implications of the results for the interpretation of cross-sectional and change scores, and for future research will be discussed. It was hypothesised that IRT scoring would show that both the MAQLQ-M and the SF-36 scales when scored conventionally, are not interval scales, and are not

equidiscriminating between levels, particularly at the extremes of quality of life.

Methods

Health related quality of life was measured using a modified version of the Marks Asthma Quality of Life Questionnaire (MAQLQ-M) and the MOS Short-Form 36 (SF-36) Health Survey (Standardised Australian Version) (6), as described in Chapter 3, "Methods". (7,8)

The partial credit version of the item response theory model, used to analyse the health-related quality of life instruments in this chapter, deals with polychotomous items where there are two or more ordered response categories for each item. (9) In this case the model estimates the probability associated with each category of each response. The equation for the partial credit model is given by

$$p(x_{ni}) = [\exp \Sigma(b_n - d_i - \tau_{ij})] / [\Sigma \exp \Sigma (b_n - d_I - \tau_{ij})]$$

where

b_n is the ability of the person n

d_i is the mean difficulty of item I across the steps

τ_{ij} is the adjustment to the mean difficulty for step j

This is a slightly simplified version of the equation for the partial credit model given in Adams & Khoo. (10) This equation is then solved iteratively. The difficulty associated with each category of each item is the calibrated score needed for a person to have a 50 per cent chance of passing that step; that is, of responding to that category rather than the next lower category. For example, Step 1 corresponds to the difficulty of passing from Category 0 to Category 1. Calibrated scale scores are given in logits. The logit is defined as the natural logarithm of the odds ratio for obtaining "correct" or positive response to an item; i.e. the probability of making a positive response divided by the probability of making an incorrect response. An item's logit difficulty is

defined as the mean of the natural logarithm of the odds that the average patient makes the transition from each category to the next higher one (i.e. the average log-odds of progressing from a rating of 1 to a rating of 2, from 2 to 3, etc).

The range of estimates in logits for a typical scale is from -4.00 (low) to +4.00 (high). (11) Since the estimates are on an interval scale, the logits may be readily transformed by a linear transformation to a scale which may be more meaningful to the users; for example with a mean value of 40 and a standard deviation of 8, to give a scale ranging from about 20 (low) to 60 (high). Although there are many possible patterns of responses that produce the same raw score when summed, there is a higher probability that the score will be based on a more consistent pattern than on a less consistent pattern.

The cases with valid data at the baseline survey occasion were scored using Quest software to carry out the item response theory procedures. (10) IRT requires "local independence"; i.e. the response of a person to an item should be independent of the responses of other persons to that item, and of responses of that person to other items. Hence the responses for other survey occasions were not included in the scale calibration analysis as this assumption would have been violated. The partial credit version of IRT analysis was used for these scales as item responses were made on a Likert scale in the surveys. Scale psychometrics were calculated, included inter-item correlation and inter-item covariance. A factor analysis was conducted using principal factor extraction to confirm the unidimensionality of the scales. The unidimensionality of a multi-item index can also, in part, be determined by the pattern of goodness-of-fit statistics. The case infit mean-square statistic examines the fit of the items, that is, the extent to which individual items are consistently related to the underlying quality of life dimension. This statistic is centred at one, and rises with increasing violation of expected results. A high mean square identifies items that produce unexpectedly high or low scores conditional on a person's ability. Such items may not be sufficiently related to the rest of the scale, or may be inconsistently interpreted

by respondents. Low item-fit statistics indicate that items measure redundant or over lapping content areas. The significance of the mean square's deviation from 1 can be tested by dividing it by its standard error, yielding an index distributed as a *t*-statistic. IRT procedures also provide fit statistics for persons, that is, the extent to which the set of responses for each person is consistent with respect to the underlying measurement model. This is measured by the infit mean-square statistic.

A partial credit analysis provides the "difficulty" associated with each category of each item, as well as the standard error associated with each item difficulty. Error terms can be used in the delineation of distinct strata along the measurement continuum. Strata have been defined as a statistically distinct level of item difficulty that is separated from other items by at least two standard errors. (12) Silverstein and colleagues have suggested that this level of separation may be too liberal, particularly in studies with large sample sizes and correspondingly small standard errors. (13) They suggest strata are segments of the scale whose centres are separated by distances greater than can be accounted by measurement error alone. They defined strata as separated by at least 0.15 logit units. (13) For purposes of this analysis a more stringent standard of 0.30 logit units was adopted.

The MAQLQ-M was analysed as a single summative scale of asthma–related quality of life, that is, as the TOTAL MAQLQ-M score. Of the eight SF-36 scales, only the Physical Functioning (PF-10) and Mental Health (MHL) scales were used. These two were felt on the basis of previous work and conceptual grounds to be likely to form ordered, unidimensional indices, that is, sampling from a single HRQL domain with items that covered a range of difficulty. For example, the PF-10 scale covers 10 items ranging from no impairment with vigorous exertion, to difficulty bathing or dressing.

Three versions of TOTAL MAQLQ-M scores were produced. These were: the mean of the standardised values of the completed items; as a simple summated Likert score; and using the item response theory procedures. The

standardised value of an item was calculated as the coded value (from 1 to 7) minus the mean value, divided by the standard deviation. This takes account of the variability in means and standard deviations across the individual items, and adjusts for cases with missing data on some items.

Results

TOTAL MAQLQ-M

The results of the TOTAL MAQLQ-M scores are summarised below (Table 1). Factor analysis using principal factor extraction was conducted, with results shown in Table 2. The eigenvalues of the first two factors were 12.8 and 1.2. Since the ratio of the first to the second factors was so high (10.6) the scale was clearly unidimensional, and no rotation was undertaken. The Cronbach alpha reliability was very high at 0.97. Table 2 shows the factor loadings for the MAQLQ-M items. The lowest factor loadings were seen with items related to being unable to sleep at night, feeling sad or depressed, feeling anxious or stressed, and feeling dependent on asthma sprays.

Table 1. MAQLQ-M scores.

MAQLQ-M	Mean	Std devn.	Min	Max
Standardised	0.0	0.76	-1.85	1.42
Likert	4.21	1.22	1	7
IRT	0.29	1.01	-5.25	4.59

Figure 1 shows the non-linear relationship between the raw TOTAL MAQLQ-M scores and the item-response theory estimates (measured in logits). The y-axis values range from 20 (20 items with code 1) to 140 (20 items with code 7). The graph has an ogive shape, seen where a bounded scale (the raw scores) is transformed to reflect an unbounded dimension (IRT estimates). The figures show an approximate linear relationship for raw scores in the range of 50 to 110. This would represent mean scores using Likert

summative scoring in the range of around 2.3 to 5.5. In this range the traditional Likert summated score would adequately represent the underlying dimension. This range would exclude approximately the top and bottom 15-20% of the study population. The departure from linearity is marked for more extreme values of raw scores.

Table 3 shows the "difficulty" associated with each category of each item. The value of category 7 for "SOB" in BREATHLESNESS is 2.15. This indicates that a "quality of life" score of 2.15 is associated with persons responding to category 7 rather than category 6. A person responding to category 6 rather category 5 would have a lower "quality of life" score of 1.55. There are no values given for category 1, since the values for category 2 show the scores associated in moving from category 1 to category 2. The highest quality of life is indicated by responding to category 7 (i.e. none of the time) for the items relating to shortness of breath, feeling tired, and feeling dependent on asthma sprays. The lowest quality of life is indicated by most frequent impairment in items relating to wheezing attacks, chest tightness, unable to do light housework, feeling sad or depressed, and feeling anxious or stressed.

Some items were associated with only mid-range values for quality of life scores even with a positive response to category 7 (i.e. "none of the time"). These items were related to social limitations due to concerns about not being able to get help, asthma preventing life achievements, feeling asthma is controlling one's life, interference with social life, and walking on level ground. These items are of lesser "difficulty" than the other items, and a lower level of the underlying dimension (quality of life) is required to achieve no impairment in these areas. Conversely, some items had higher quality of life scores with responses to category 2 than other items. That is, a higher quality of life is needed in order to have any respite at all from problems in these areas (i.e. to move from answering "all the time" to "most of the time"). These items related to feeling dependent on asthma sprays, and inability to walk uphill.

Although the principal factor analysis showed one dominant factor, it is helpful to view the results by the MAQLQ-M sub-scales, as this allows easier visualisation of the items and the spread of item difficulties across the HRQL range in logits. What can be seen is that in each specified sub-scale domain there is a hierarchy of item difficulty at the extremes of the response range, ie points 2 and 7. In the middle of the possible responses there is greater variation in the Likert responses that correspond to the logit scores on the IRT model.

Table 4 shows the standard errors associated with each item difficulty. The standard errors are smaller for categories in the centre of the range from 1 to 7, indicating better precision of measurement at the centre of the range than at the extremes. The case infit mean square statistic indicates the extents to which individual items are consistently related to the underlying "quality of life" dimension. Figure 2 shows the fit of the items, that is, the extent to which individual items are consistently related to the underlying HRQL dimension. Values higher than 1.3 indicate items with poorer fit. Items 10, 11, 12, and 25 (being unable to sleep at night, feeling sad or depressed, feeling anxious or stressed, and feeling dependent on asthma sprays) had a relatively poorer fit, confirming the results of the factor analysis that also identified these as the weaker items. None of these however exceeded the in-fit statistic criterion indicating significant departure from the model. Items with a fit value less than 0.70, (item 20, "I have felt generally restricted"), have a fit better than predicted by the underlying measurement model.

IRT procedures provide fit statistics for persons as measured by the infit mean-square statistic. Figure 3 shows the frequency distribution of infit mean square values for persons on the baseline surveys. Values greater than 1.3 demonstrate increasing inconsistency. Most of the cases fall below this limit, but there are some cases with higher values. Their MAQLQ-M estimates are therefore less reliable, in the sense of departing from the underlying measurement model. However, all items had values below +2.00, which because the infit statistic follows a *t*-distribution, this is the value that is near

the 0.05 probability of occurrence.

SF-36

Table 5 shows the factor loadings and Cronbach Alpha coefficients for the SF-36 scales of Physical Functioning (PF10), and Mental Health (MHL). For each there is one dominant factor, indicated by a high ratio of first to second eigenvalues. The PF-10 coefficients show that items 1 ("vigorous activities") and 10 ("bathing and dressing") were the weakest item parts of this scale. The reliabilities of these scales are shown in Table 6. The IRT reliability of items shows the consistency with which items are operating across cases. The IRT reliability of cases shows the consistency with which cases are operating across items (corresponding to the normal meaning of reliability in traditional analysis). The reliability values showed all items were of adequate fit to the model. The Cronbach alpha values are also generally high.

Table 7 shows the summary of item response theory analyses sorted by items for the PF-10. The hierarchy of items defined by the IRT analysis for the PF-10 scale differs somewhat from the order of administration (and the assumed order of difficulty), in the SF-36 survey. For example, walking up any number of stairs is more "difficult" than carrying groceries, which is a task that is of similar "difficulty" to bending or walking half a kilometre. The scale also demonstrates crowding of item logit values in the middle of the range, with few items covering the extremes of the spectrum of HRQL. For example, moving from the item with the second highest value (not limited at all in "climbing several stairs") to the highest scoring item (no limits in "vigorous activities") requires an improvement in the underlying trait of HRQL of around 1 logit. Using summative scoring methods this would increase a persons score by about 5 points only. A similar amount of actual improvement in HRQL (ie 1 logit) gained in the middle of the scale, would mean changing categories (from limited a little to not limited) for 5 or 6 items. This would bring about a summative score change of around 30 or more points. Similarly, at the opposite end of the scale, to move from being limited a little

in "bathing or dressing" to the next item of limited a little in "walking 100 metres" requires an improvement in underlying HRQL of about 1 logit.

It is also evident that there is not equal meaning of changing from "limited a lot" to limited a little" and from "limited a little" to "not limited at all" across all items. In other words these steps do not have equal meaning for different scale items. Greater gains in actual HRQL are needed to move from "limited a little" to "not limited at all" for items at either ends of the PF-10 scale than for those items in the middle of the HRQL continuum.

The 5-item Mental Health scale also demonstrated a hierarchical and unidimensional structure (Tables 6 & 8). Again, when viewing the table with the interval logit scale down the left hand side, and comparing these with the distances between responses given on the Likert scale, it can be seen that the Likert responses are not at the interval level of measurement. It is also clear that each step on the response scale (eg moving from 4 to 5) had different meanings for different items. Further, while there is a definite hierarchy of difficulty for items at the higher levels of HRQL, this pattern is not so consistent in the middle ranges of mental health.

Discussion

MAQLQ-M

The results confirmed that the MAQLQ-M met the requirements of the IRT model. These requirements include the identification of a hierarchical index which is focused on a single dimension. These results have important implications for the validation of the MAQLQ-M and for understanding how items and people can be placed along the continuum of asthma-related quality of life. The data provide direct support for use of an IRT-based measure of asthma-related quality of life for purposes of estimating HRQL in asthma across populations and over repeated tests.

Although the focus in item response theory is on the individual items, there are many occasions where it is desirable to produce a scale consisting of a set of common items, as in quality of life scales. Under the item response theory model, the total raw scores calculated by summing the code values for the variables are sufficient statistics for the estimation of severity. For each given total raw score there is a corresponding scale score estimate (in logits) and an associated standard error.

Under the partial credit model, it is possible to estimate the severity associated with each category of each item in the calibrated MAQLQ-M. In Table 3 the response categories of the all items in the MAQLQ-M are presented in the order of the scale values (difficulties). By reading the tables horizontally, across the items, consistent patterns of severity may be identified. By reading down the columns it can be seen that the categories of the items are not evenly spaced across the scale, as would be expected if the variables were at the interval level of measurement. Individual items of the MAQLQ-M mapped out a hierarchy of asthma-HRQL, with good spacing along the continuum of HRQL. This can be seen by considering the logit values of the extreme anchoring points, signified by the response scores of 2 and 7, which represent the "highest" and 'lowest" HRQL a particular item covers. Thus, individuals can be mapped onto a continuum by examining their responses to individual items, both for overall asthma-HRQL, and in each of the separate domains where there may be particular issues of clinical interest. The non-sample dependent nature of the IRT model allows comparison across populations in which the *items* themselves are valid. As the MAQLQ-M has shown good validity in a variety of populations previously (6,14,15), this provides confidence that cross-population inferences can be drawn. Although the analysis demonstrated a strong underlying unidimensional index, examining the logit values for each individual item can demonstrate the value of considering the MAQLQ-M as comprising of various sub-scales. Table 3 shows good spread of items along the continuum when grouped into the sub-scales of the original MAQLQ-M. (6) However, take together as a whole, with all the items forming a single scale, there is greater

overlap, particular between the SOCIAL and CONCERNS sub-scales, and the BREATHLESSNESS and MOOD sub-scales. This means a more simplified questionnaire with fewer items may be able to be administered which can map out the HRQL continuum adequately, by selecting a number of items from each sub-scale that cover different levels of HRQL. Conversely, if an intervention trial is expected to produce results predominantly within one area, eg mood or breathlessness, than this sub-scale could be given alone and should provide good information of asthma-HRQL. Future work could address the question of what information is lost versus what is gained from this approach, in a variety of research settings. An analogous approach has been used by the developers of the SF-36, in an attempt to see if an SF-12 is adequate to describe HRQL, albeit utilising a different analysis model. (16,17)

Further research on the MAQLQ-M could include additional questions aimed at the extremes of the HRQL range to assess if this adds to measurement precision as well as scale unidimensionality and reproducibility. Within an IRT model it is not necessary to give the same items to all persons. For example, if easy items are given to persons of high ability they contain no information that is useful in deciding the location of that person on the scale. Similarly, no useful information is obtained by giving hard items to persons of low ability. Although the easy adaptation of this reasoning to testing requires the use of computerised data banks of items (1,3), it may be possible to adapt this approach within certain well-defined populations with known levels of ability, eg athletes or hospitalised patients.

The analysis demonstrated the non-linearity of the Likert summative scoring model at the ends of the HRQL range. This would include about a fifth of the study population, and these individuals are often the ones where clinical interest and concern is greatest. These results suggest caution should be made in interpreting differences between, and changes in HRQL with time, in individuals and populations with either very good or very poor HRQL, when the MAQLQ-M is scored in the traditional summative manner. Further work could examine the clinical utility of using bands of severity in such populations

to estimate HRQL, rather than relying on summative scores. For those with mid-range scores, and these may well be the majority of persons with asthma, the usual scoring model would be adequate.

The goodness-of-fit analysis is intended to provide a guideline to estimate the ability of items to fit within a common dimension. The probabilistic nature of the model anticipates departures from an entirely predicable pattern of responses, as would be obtained with a pure Guttman scale. Although four items had values that showed some tendency to deviate from the underlying measurement model, none was significant. Item-fit statistics above the threshold of +2.00 have unpredicted and variable response patterns for some patients, and thus are candidates for further inspection and analyses. The four items with statistic values of greater than 1.3 ("feel sad", feel anxious or stressed, unable to sleep, and feel dependent on sprays") may be examined for potential reasons for some deviance from the model. A general concern with these (and perhaps other items) is the extent to which persons respond differentially to one or more of the indicator activities within each item, eg "anxious or stressed", could be interpreted differently by individuals. A related concern is the extent people score these items by personal criteria unrelated to asthma, or are indicating problems in life-quality that are unrelated to asthma, eg depression and sadness or sleep deprivation. Despite explicit instructions in the survey, it is difficult for individuals to measure out the precise impact of various co-morbidities when answering these more general questions.

Deviations of the observed item scores from the expected scores can be examined for individuals as well. This provides an important check on the validity of a score to estimate asthma-HRQL. (18) One of the advantages of the IRT model is that such variation does not necessarily invalidate the scale or the person's summary score, but instead draws attention to an item pattern that is different than that recorded by the majority of persons. (18) The person fit statistics may be used to assist in diagnosis. Mis-fitting cases (with an inconsistent pattern of responses) may indicate problems in responding to

the questionnaire. On the other hand, an abnormal pattern of responses may indicate a real condition warranting more detailed clinical examination. Further advantages for the IRT model is in interpretation of individual scores is in cases with missing data. (18) It is preferable to use the actual estimates derived from the item response theory program for these cases, because IRT utilises expected score information when accounting for missing data. This pattern-specific handling of missing data uses the available scaling model information to provide a best estimate of the missing item and the overall score. (18)

SF-36

This analysis supported the hierarchical, unidimensional nature of the PF-10 and the MHL in asthma subjects. Like the results for the MAQLQ-M, this has important implications for our understanding of the continuum of both physical functioning and mental health in asthma. The hypothesised ordering of the PF-10 as implied from the order on the SF-36 survey was not seen in the IRT analysis. This is similar to results seen in previous analyses which have used a Rasch rating scale model, that have assumed a similar pattern of difficulty associated with the common three-point rating scale. (4,12,18) The results confirmed that the PF-10 items represented a unidimensional construct of physical functioning in asthma subjects, further confirming its face validity in asthma.

The 10 items of the PF-10 are spaced across the continuum. Using a value of 0.30 logits to separate strata, 7 distinct bands at the "no limits" level are seen. However, there is a notable gap in the coverage of the continuum between the items of "vigorous activities" and "walking several flights of stairs", and then a further large gap to "walking more than one kilometre". At the other end of the spectrum, there is large gap in coverage moving from "bathing" to "walking 100 metres" to "bending". Six items crowd into the middle of the HRQL continuum. Hence, it is clear that the extremes of the scale are less well covered by the items currently in the PF-10 of the SF-36

than the mid-range of HRQL. This is also similar to previous results in other populations. (4,12,18) One of the implications of this is that the traditional summative scoring will produce erroneous results when comparing heterogeneous populations, or changes that occur at different levels of the underlying dimension of HRQL. Change scores will depend to a large extent on where the individual started on the underlying trait, or in other words, how much impairment was present to begin with. (4) There are therefore grounds for considering that additional items could be developed that would be positioned at either end of the scale that represent higher- and lower-order physical activities. (12)

Another aspect of interpreting scores is that it is not necessary to answer "no limits" to a particular item before moving from "limited a lot" to "limited a little" for the next item". Thus it is possible to answer "limited a little" to 5 questions before achieving "no limits" in bathing (Table 7). A display of results for an individual patient similar to Table 7 that allows the carer to visualise results and take these points into account may assist in identifying problem areas more readily than a simple summated score.

There was a considerable gap in the coverage of mental health at the upper end of the MHL scale, with a gap of around 1.4 logits between maximum responses for "happy" and "down". This was mostly due to the large difference in logits between feeling "down" a little of the time and none of the time, emphasising that this item is not equidiscriminating throughout the mental health continuum.

Summary

This hypothesis that the traditional summative scoring methods for the MAQLQ-M and SF-36 do not produce scales at the interval level of measurement, nor are equidiscriminating throughout the asthma-HRQL continuum is proven. The analysis has shown that gaps in coverage are pronounced at the extremes of HRQL for both scales, but that this is more

marked for the two SF-36 scales than for the overall MAQLQ-M. The results provided important prerequisite information for the validation of an aggregate measure based on item hierarchy and that is unidimensional for asthma-HRQL. IRT scoring methods can allow the valid use of these instruments in comparison studies across populations. The knowledge of raw scores can allow clinicians to place individuals on the continuum of asthma –related quality of life. The examination of inconsistent responses by individuals can point to problems warranting clinical investigation. These results mean that these further studies of the clinical utility of the IRT model can be made with confidence as to the validity of the scales as unidimensional, hierarchical scales of health-related quality of life.

Once items from a given scale have been calibrated by means of item response theory they can be entered into a bank of similar items. Items from other scales can also be entered into the bank of items provided there are sufficient common items across the scales to enable calibration adjustments to be undertaken. For any given diagnostic use or research study, a set of items may be taken from the item bank to produce a calibrated scale at the interval level of measurement. This permits comparability across uses or across studies without constraining the specific items to be used. This analysis has shown deficiencies in these instruments at both ends of HRQL status. The addition of further items to increase coverage at the ends of the HRQL spectrum can be calibrated and validated using IRT. Items could be selected from the instruments for use in studies in order to maximise coverage at particular levels of health status (eg severe). This could reduce the response burden for subject, or allow further items to be added that increase measurement precision around this level of health status.

Table 2. Principal factor analysis of MAQLQ-M.

Item	Factor loading
SOB	0.80
Wheeze	0.71
Tightness	0.72
Walking	0.82
Light h/w	0.83
Uphills	0.78
Heavy h/w	0.83
Tired	0.74
Sleep	0.64
Sad	0.61
Anxious	0.62
Frustrated	0.72
Achieve	0.85
Soc. Life	0.85
Places	0.76
Get help	0.76
Sport	0.82
Restricted	0.88
Control me	0.85
Future	0.80
Short life	0.73
Sprays	0.57
Eigenvalue	12.83
Variance explained	0.82
Alpha (Cronbach)	0.97

Table 3. MAQLQ-M - Breathlessness.

Logits	SOB	Tight	Uphill	Wheeze	House-heavy	House-light	Walk-Level
2.2							
2.1	**7**						
2.0							
1.9							
1.8							
1.7		**7**	**7**				
1.6							
1.5	6			**7**			
1.4							
1.3					**7**		
1.2		6					
1.1							
1.0			6	6			
0.9	5					**7**	
0.8							**7**
0.7					6		
0.6		5		5			
0.5			5				
0.4						6	
0.3					5		6
0.2							
0.1	4		4			5	
0							5
-0.1					4		
-0.2		4					
-0.3			3	4			
-0.4					3		
-0.5						4	4
-0.6	3						
-0.7							
-0.8			**2**				3
-0.9		3					
-1.0				3		3	
-1.1					**2**		
-1.2							
-1.3							
-1.4							
-1.5							
-1.6							
-1.7	**2**						
-1.8							
-1.9							
-2.0		**2**					**2**
-2.1							
-2.2							
-2.3							
-2.4						**2**	
-2.5				**2**			

Table 3. MAQLQ-M - Social.

Logit	Places bad	Sports	Restricted	Social	Controlling	Prevent achieve	Afraid places
2.2							
2.1							
2.0							
1.9							
1.8							
1.7							
1.6							
1.5							
1.4							
1.3							
1.2	**7**						
1.1		**7**					
1.0			**7**				
0.9							
0.8				**7**	**7**		
0.7		6				**7**	
0.6	6						
0.5							
0.4			6	6	6		**7**
0.3	5					6	
0.2		5					
0.1			5	5		5	6
0					5		
-0.1							
-0.2		4				4	
-0.3					4		5
-0.4	4		4				
-0.5		3		4			
-0.6					3	3	
-0.7			3				
-0.8	3						4
-0.9				3			
-1.0							
-1.1							3
-1.2							
-1.3		**2**					
-1.4					**2**	**2**	
-1.5				**2**			
-1.6	**2**						
-1.7			**2**				
-1.8							**2**
-1.9							
-2.0							
-2.1							
-2.2							
-2.3							
-2.4							
-2.5							

Table 3. MAQLQ-M - Concerns.

Logit	Depend Sprays	Frustrated	Future	Short life	Controlling	Prevent achieve	Afraid places
2.2							
2.1	**7**						
2.0							
1.9							
1.8							
1.7							
1.6							
1.5							
1.4		**7**					
1.3	6						
1.2							
1.1			**7**				
1.0				**7**			
0.9	5						
0.8		6			**7**		
0.7			6			**7**	
0.6							
0.5				6			
0.4	4		5		6		**7**
0.3		5				6	
0.2	3			5			
0.1						5	6
0					5		
-0.1							
-0.2			4			4	
-0.3	**2**	4		4	4		5
-0.4							
-0.5							
-0.6			3	3	3	3	
-0.7							
-0.8		3					4
-0.9							
-1.0							
-1.1				**2**			3
-1.2							
-1.3			**2**				
-1.4					**2**	**2**	
-1.5							
-1.6							
-1.7							
-1.8							**2**
-1.9		**2**					
-2.0							
-2.1							
-2.2							
-2.3							
-2.4							
-2.5							

Table 3. MAQLQ-M - Mood.

Logit	Tired	Sleep	Anxious	Frustated	Sad
2.2					
2.1					
2.0	**7**				
1.9					
1.8					
1.7		**7**			
1.6					
1.5			**7**		
1.4				**7**	
1.3	6				
1.2					
1.1					**7**
1.0		6			
0.9			6		
0.8	5			6	
0.7					
0.6		5			6
0.5					
0.4			5		
0.3				5	
0.2	4				5
0.1					
0					
-0.1		4			
-0.2					
-0.3	3		4	4	
-0.4					
-0.5					4
-0.6		3			
-0.7					
-0.8			3	3	
-0.9					
-1.0					3
-1.1					
-1.2					
-1.3					
-1.4					
-1.5	**2**				
-1.6					
-1.7					
-1.8					
-1.9				**2**	
-2.0					
-2.1		**2**			
-2.2					
-2.3			**2**		
-2.4					**2**

Table 4. IRT item difficulty MAQLQ-M – standard errors

Item	Err2	Err3	Err4	Err5	Err6	Err7
SOB	0.31	0.24	0.22	0.24	0.29	0.33
Wheeze	0.38	0.24	0.22	0.22	0.23	0.24
Tightness	0.34	0.24	0.22	0.22	0.25	0.26
Walking	0.34	0.25	0.24	0.21	0.21	0.21
Light h/w	0.38	0.27	0.23	0.22	0.21	0.19
Uphills	0.22	0.22	0.20	0.20	0.23	0.24
Heavy h/w	0.22	0.22	0.21	0.22	0.20	0.22
Tired	0.25	0.22	0.21	0.23	0.24	0.29
Sleep	0.31	0.23	0.21	0.21	0.23	0.26
Sad	0.38	0.25	0.23	0.21	0.22	0.20
Anxious	0.34	0.23	0.22	0.20	0.23	0.25
Frustrated	0.31	0.024	0.23	0.21	0.22	0.23
Achieve	0.28	0.22	0.22	0.21	0.21	0.21
Soc. Life	0.28	0.26	0.23	0.22	0.21	0.21
Places	0.28	0.24	0.23	0.21	0.22	0.23
Get help	0.34	0.28	0.26	0.22	0.21	0.20
Sport	0.25	0.23	0.21	0.22	0.20	0.22
Restricted	0.28	0.23	0.23	0.21	0.21	0.22
Control me	0.25	0.23	0.23	0.20	0.21	0.20
Future	0.27	0.23	0.22	0.20	0.22	0.21
Short life	0.23	0.22	0.23	0.22	0.21	0.21
Sprays	0.20	0.20	0.21	0.23	0.24	0.31

Figure 1. Total AQLQ-M estimate (logits) vs raw scores (Likert) at baseline.

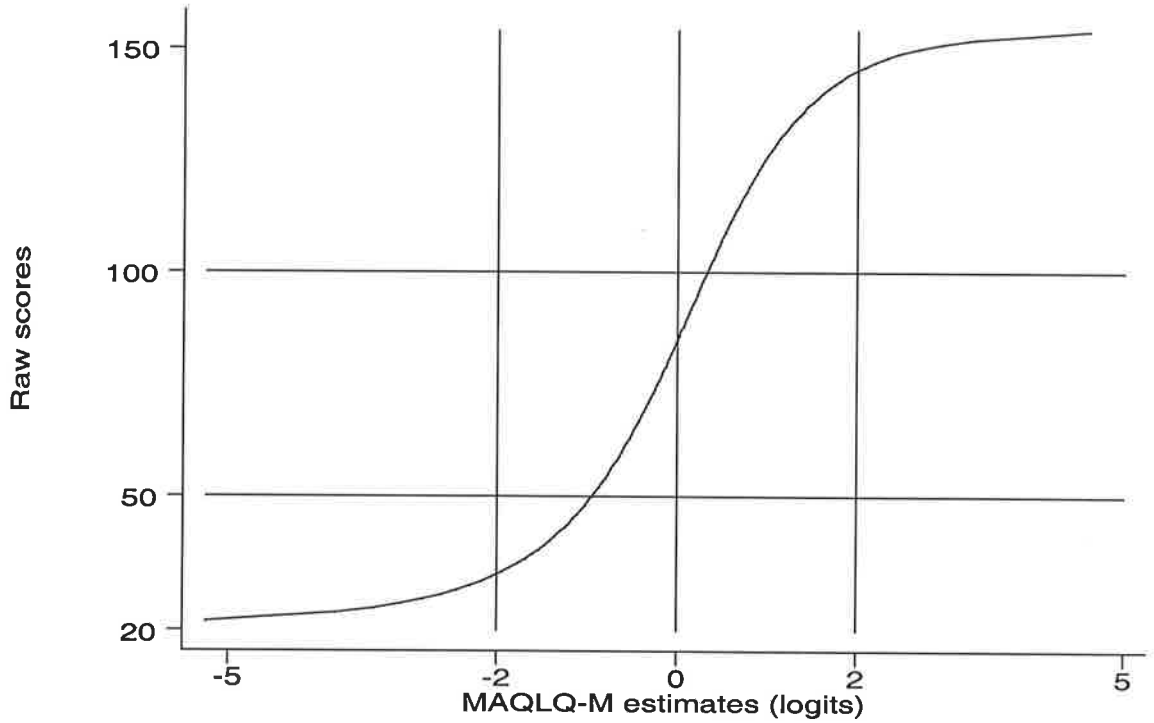

Figure 2: Frequency distribution of item inconsistency values.

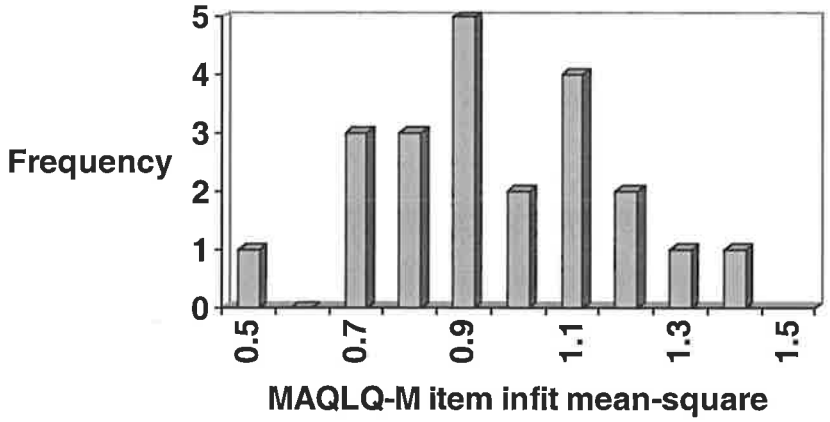

Figure 3: Frequency distribution for case inconsistency scores (infit mean-square)

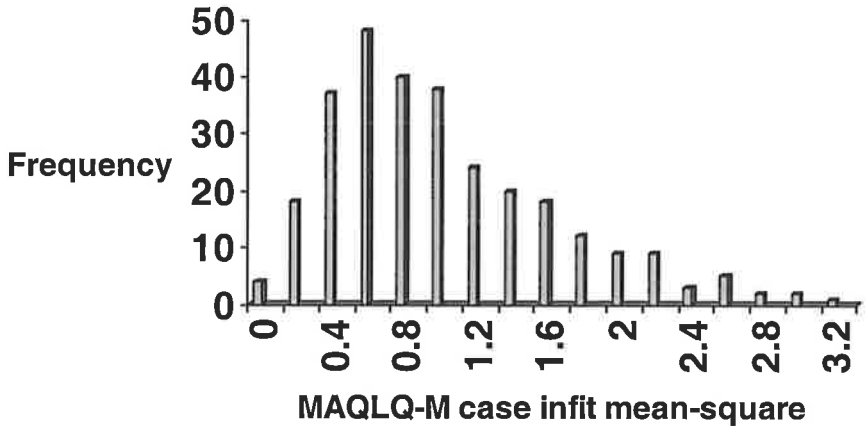

Table 5. Principal Factor analysis – SF-36 PF-10 & Mental health scales.

Item *PF-10*	Factor loadings	Item-test correl.	Item-rest correl.
Vigorous	0.57	0.62	0.54
Moderate	0.75	0.78	0.72
Lifting	0.80	0.82	0.76
Several stairs	0.71	0.75	0.68
One stairs	0.84	0.86	0.81
Bending	0.72	0.76	0.70
>One Kilometre	0.81	0.82	0.77
Half kilometre	0.85	0.85	0.81
100 metres	0.73	0.75	0.69
Bathing	0.53	0.58	0.51
Eigenvalue	5.54		
Alpha	0.92		
Mental Health			
Nervous	0.56	0.69	0.48
Dumps	0.79	0.83	0.71
Calm	0.65	0.72	0.55
Down	0.71	0.76	0.62
Happy	0.66	0.73	0.58
Eigenvalue	2.31		
Alpha	0.80		

Table 6. SF-36 Reliabilities.

Scale	Items	Cases	Alpha	Comments
PF-10	0.95	0.87	0.92	All items OK
MHL	0.60	0.68	0.80	All items OK

Note: See text for Table interpretation.

Table 7. Item response values for SF-36

SF-36: Physical Function (PF-10)

Logit	Vigorous	Several stairs	>1 km.	Moderate	One flight stairs	Lifting	½ km.	Bending	100 m	Bathing
6.0	**Not**									
5.0		**Not**								
4.0										
3.0										
2.0	Little		**Not**	**Not**						
1.0		Little			**Not**	**Not**	**Not**	**Not**		
0				Little						
-1.0			Little		Little				**Not**	
-2.0						Little	Little			**Not**
-3.0								Little		
-4.0									Little	
-5.0										Little

Table 8. Item response values for SF-36: Mental Health (MHL).

Logit	Down	Happy	Nervous	Calm	Dumps
3.0					
	5				
2.5					
2.0					
1.5					
		5			
			5		
1.0					
	4				
				5	
0.5			4		**5**
	3				
		4	3		
0				4	
			2		4
	2				
		3			3
-0.5				3	
			1		2
		2			
				2	
-1.0	**1**				
					1
		1			
-1.5				**1**	
-2.0					
-2.5					

Chapter 8

Self-management Autonomy preferences and Physician participatory decision-making style in asthma.

Introduction

Recently, authors in the medical and popular literature have noted a shift in patient attitudes towards a more "consumerist" approach to health-care. (1,2) Implicit in this is the notion of the individual acting as an autonomous, rational actor in the medical encounter, and rejecting the model of the 'passive' or 'dependent' patient. This conception is allied with the sociological notion of the "reflexive project of the self". (3) In this formulation, life is a project requiring a continual search for knowledge in order to gain self-improvement. Expert knowledges such as medical science are not accepted at face value and are subject to sceptical questioning and evaluation. Lupton has found that these approaches to the medical encounter fail to recognise its complexity and changeable nature. (3) Individuals may be both "consumerist" and "passive patient" simultaneously and variously, depending on the context, and on their personal and socio-cultural characteristics.

Although consensus guidelines for asthma management have emphasised the importance of enhancing patient self-management in asthma through increased autonomy in decision-making (4-6) little research has been done to ascertain the patients' attitudes to this management approach. Even less work has sought to examine the factors that may predict or influence these attitudes. Gibson and colleagues demonstrated that asthma patients did not show strong preferences for having a major role in decision-making. (7) This work did confirm that, in common with many other conditions, asthma patients wish to be fully informed about their illness. (8,9) Recently, Deber et al have suggested that the scales used in studies that showed low desires for autonomy were flawed in that they failed to differentiate between two aspects of choice behaviour. (10) These authors identified problem-solving (PS) as a

process of identifying the correct solution or the best options, as a separate concept from decision-making (DM). They contended that PS tasks required expertise and most people feel would sensibly be left largely to professionals. Decision-making required making trade-offs and choices between alternatives, and patients may be expected to desire involvement in them. They reported patients did not wish to be involved in problem solving, but desired shared decision-making with doctors. (10)

Evidence from other conditions indicates that patients who more actively question doctors and express opinions have better health outcomes. (11-14) Other authors have shown that interventions to increase patient involvement in decision making lead to better outcomes for a number of chronic illnesses, such as diabetes. (12,15) A recent systematic review indicated that effective physician-patient communication was associated with improved health outcomes. (16) Agreement between physician and patient was found to be a key variable that influenced outcomes, implying that "decision-making was a shared, egalitarian process", and that patients benefit from "engagement in a process that leads to an agreed management plan". (16) A large body of research has consistently shown a strong relationship of communication to patient satisfaction. (17)

A small body of literature has been concerned with using the physician as an agent of change in encouraging greater patient involvement in treatment decisions, although little of this work has involved asthma. (11,15) Certain patient characteristics, such as age and educational level, appear to be related to the propensity of physicians to involve their patients in treatment decisions. (18) These characteristics also seem to be associated with patient desires for autonomy in decision making. (8) If patient involvement in management leads to better outcomes, and the doctors' behaviour is critical to this, then ascertaining the factors that influence these behaviours may have significant potential benefits in asthma management.

It would be valuable to be able to identify those factors that independently contributed to the degree of self-management autonomy preferred by asthma subjects. This would contribute to our understanding of how patients approach self-management and how a framework is constructed by patients to cope with asthma, and its management, in their lives. This has significance for our understanding of treatment adherence with regular therapy and for effective management of acute attacks of asthma. It may define important areas for education and self-management programs to focus on in order to improve treatment and outcomes. Particular sub-groups of the asthma population may be described for whom encouraging autonomy is not appropriate. Other groups may require specific skills or have their concerns addressed.

This chapter examines the issue of patient preferences for asthma self-management autonomy and how this is related to clinical measures of asthma, personal characteristics and attitudes, and to the participatory decision-making (PDM) style of the attending physician. Organisational factors such as length of office visits and the impact of provider switching in clinics and the effects of these on the PDM style of the physician are also described. The instrument used is the decision-making scale as refined for asthma by Gibson et al from the original Autonomy Preference Index (API) of Ende et al. (7,8) The validity of the scale was also investigated, as Gibson et al did not publish validity data from their asthma sample. The data from asthma patients was also tested to see if there was evidence to support the thesis of Deber and colleagues regarding the decision-making and problem-solving construct of autonomy. The Participatory Decision Making (PDM) style of managing physicians was assessed by the measure described by Kaplan et al. (18,19)

The information-seeking component of the API was not administered. This was because in all previously published studies the desire for information has been universally very high, and it was felt minimal new information would be

gained to offset the burden on the patient of answering further numbers of questions. (7,8,10)

Methods

Surveys were administered at baseline and at the 12-month follow-up period. The questionnaires were sent via post to all subjects, along with the battery of other measures as described in Chapter 3, 'Methods'. To investigate test-retest reliability, the autonomy preference index (API) was presented to a sub-group of 67 subjects on two occasions, 1-2 weeks apart, (mean time to repeat testing was 11 days). The intraclass correlations for the scales were calculated by the method of Deyo et al. (20) Internal consistency of the index was assessed using Cronbach's alpha coefficient.

Autonomy

To investigate test-retest reliability, the autonomy preference index (API) was presented to a sub-group of 67 subjects on two occasions, 1-2 weeks apart, (mean time to repeat testing was 11 days). The intraclass correlations for the scales were calculated by the method of Deyo et al. (20) Internal consistency of the index was assessed using Cronbach's alpha coefficient.

Concurrent validity is difficult to establish for a scale measuring patient prefences for decision-making autonomy. Apart from this index there is little in the literature with which to compare responses to this scale. There are no physiological or other objective markers available to test convergence, ie the presence of associations between variables that, on the basis of experience, would be expected to associate well, as are used for quality of life measures. Ende and colleagues established concurrent validity by correlation with a global item of attitude to medical care. (8) As the adaptation of the index for asthma did not have previously reported validity data, the method of Ende et al was replicated here in order to establish validity for use in asthma patients, when compared to the original index. The 67 subjects used for determining

test-retest reliability had a global question appended to the instrument. This item offered five responses to the question: "Regarding your asthma, which statement best describes your attitude towards medical care?". The response choices were: "The patient should take complete control", "The patient should have more control than the doctor", "The patient and the doctor should share control equally", "The doctor should have more control than the patient", "The doctor should take complete control".

The predictive validity of the index can be assessed in two ways. Firstly, by its ability to predict behaviour in both chronic and acute asthma self-management, and secondly by whether this behaviour can predict future health or health-care needs. The relationship of the API to future health and hence the indirect validity of the index, is dealt with in Chapters 9, 'Risk factors for hospital admissions, readmissions, and recurrent presentations to hospital emergency departments. No data was collected regarding patient behaviour in acute attacks, thus making its predictive validity an area for future research.

The API was designed to measure preferences in a number of clearly defined asthma exacerbation scenarios, and general attitudes, according to clinical situations defined on the basis of experience. Whilst commonsense would suggest the items for each respective scenarios would be closely related to one another, and less well related to other items in the index, this had not been formally analysed to explore the structures of responses. If the contention of Deber et al is correct, then a more complex pattern may emerge in which purely DM items would separate from PS or mixed items. (10) A factor analysis was performed to establish to what extent the items did accord in measuring common themes and whether the items fell into the expected groupings. Factors were extracted using principal components analysis. The advantages in this situation of using principal components over principal factor analysis with regard to ease of computation of scores and in explaining as much of the variance as possible has been discussed by Ware et al. (21) Rotation is appropriate where there are approximately equal numbers of

items relating to the different constructs, as was anticipated here. (22) There are good theoretical arguments for both orthogonal and oblique factor rotations. (23) Orthogonal rotations may have advantages in testing construct validity and interpreting the scales. (21) Criteria commonly used to evaluate factor analysis using the principal components method were routinely applied. Eigenvalues greater than unity are required for rotation. (24) Other criteria, previously used, including the scree test, five percent rule, and common factor test were also satisfied. (23) Prior to the analysis a strong association was defined as a correlation greater that 0.70, a moderate to substantial association as a correlation of 0.3 to 0.7, and a weak association as a correlation of less than 0.3. (25)

Comparisons between each of the scenarios and between hospitals were made by means of Analysis of Variance (ANOVA). Relationships between scales, and with other variables were assessed by using Pearson's product moment correlation. Given the large number of associations studied the importance of statistical significance at the conventional $p<.05$ level should be treated with some caution. However, these values provided the basis for inclusion of variables into multivariate models in a parsimonious manner. (26) To assess which variables were the most important predictors of decision-making autonomy preferences, multivariate analyses were conducted. Forward stepwise multiple linear regression was performed to identify which independent variables contributed a significant amount of variance. It would also be useful to ascertain if differences were seen for those who favoured the doctor retaining control over decisions, and those who preferred to retain control themselves. Logistic regression also provides odds ratios that are intuitively often easier to interpret. Multiple logistic regression models were performed for the dichotomous outcome variable of autonomy score above and below the mid-point of the index (ie score of 3), which is the point where subjects felt doctor and patient should be equally involved in decisions. That is, for those who favour the doctor to make decisions, and those who favour the patient to do so. Calculations were performed on the LogXact statistical package, using asymptotic inference methods. (27)

Responsiveness to change over 12-months was operationalised in three different ways. The ability of the instrument to detect within subject changes was compared by means of paired t-tests. The ability of the index to detect any differences between the TQEH group and the LMHS group was done by subjecting the change scores to analysis of covariance (ANCOVA) with the TQEH group used as a factor and the baseline scores used as covariates using the Statistica software package. (20,28) Finally, effect sizes were calculated for both groups in two ways. Firstly, effect size was calculated as the raw score change from baseline to follow-up divided by the standard deviation of the index scores at baseline. (29) Secondly, the standardised response mean, a value not affected by sample size (30), was calculated by dividing the mean change in score by the pooled within-subject standard deviation of individuals' changes in scores from both groups. (20)

Participatory

At the 12 month follow-up only, patients were asked to complete a satisfaction questionnaire in addition to the other components of the survey. This included the 3-item measure of Participatory Decision Making (PDM) style as described by Kaplan et al. (18,19) The satisfaction survey was derived from that published by the Health Outcomes Institute, 1994. (34) This survey was administered at 12-month follow-up only as it was originally intended as part of the evaluation of the intervention, and also because the need for follow-up visits was entirely at the discretion of the attending physician, hence no reliable estimations for clinic follow-up could be made for each individual. The risk of biasing the results with non-randomly missing variables at follow-up was considered sufficient to make follow-up data unreliable for analysis.

PDM style was assessed as the aggregate of 3 items, asking the patient to rate their doctors' propensity to: 1) involve them in decisions regarding choices between treatments; 2) give them a sense of control over their treatment; and 3) ask them to take some responsibility for their treatment.

(18,19) The unadjusted mean, 95% confidence intervals and internal consistency reliability of this measure is presented in Table 12.

Three characteristics of the clinic visit likely to influence PDM style were measured by patient self-report. These were the length of the clinic visit; the tenure of the particular physician-patient relationship; and the tenure of the hospital-patient relationship regarding "chest problems". These were taken as a proxy for the familiarity of the doctor and patient, and to determine if continuity of care with a particular doctor in outpatients was of more significance than the length of time a person had been attending the hospital clinic. This was done to investigate if there were any negative consequences of provider switching within a single outpatient clinic. No objective or external measurement of these variables was made. Also included was a single-item rating of patient's overall health status on a five-point scale, ranging from excellent to poor. Other patient characteristics that were hypothesised to influence PDM style were age, gender, marital status, country of birth and educational level.

Short-term test-retest reliability was not assessed as the measure was only administered on one occasion. Variations in PDM style related to various patient and visit characteristics are shown. Comparisons are based on t-tests for mean differences between groups. Correlations between PDM style and all variables listed here are reported. A logistic regression model was developed to predict a dichotomous variable for style based on the mid-point of the scale, ie whether a physician was more or less likely to encourage patient participation in decision-making. Calculations were performed on the LogXact statistical package, using asymptotic inference methods. (27)

Results

Autonomy

A total of 286 subjects completed the baseline survey, and 221 responses were received at the 12-month follow-up. When compared for age, gender, baseline symptoms or quality of life scores, or household income, the baseline and 12 month follow-up group did not significantly differ. The 67 subjects used in the test-retest reliability study did not differ from the full study population, when compared for these criteria.

Reliability and Validity of the index

To examine test-retest reliability, the intraclass correlations obtained for the scales are shown in Table 1. (20) These showed acceptable reliability of the index, as defined by Helmsteder for attitude tests. (31) Nunnally & Berstein have suggested levels of reliability of 0.90 or greater are needed for scales used in individual decision-making. (23) The values of greater than 0.90 indicate that an estimated <10% of the observed variance is due to error in measurement.

Internal consistency of the index was assessed using Cronbach's alpha coefficient as shown in Table 1. Minimum standards of reliability for both group comparisons and for individual respondents were satisfied. (21,31) Item internal consistency is conventionally supposed to be satisfactory if the correlation between the item and the scale is at least 0.40. (23,31) These levels were obtained for all items except Question 5, dealing with the issue of when to see a doctor in the event of a mild-moderate asthma exacerbation. Thus the autonomy preference index has acceptable reliability for use in adult asthma patients.

Concurrent validity was estimated by correlation with a global item of patient's attitudes to medical care. Patients' responses to this item correlated significantly with their decision-making scores ($r = 0.65$, $p < .00001$).

The structure of responses: Factor analysis

The correlation matrix contained many coefficients > 0.3 suggesting it could be meaningfully factored. The number of cases in the whole sample was adequate, as it was larger than 10 times the number of variables. (23) Although the item responses are categorical, the summed scores form a continuous distribution, which satisfied tests of normality (Shapiro-Wilk $p > 0.05$). Thus principles appropriate for use of factor analysis were satisfied. (24)

A two-factor solution was obtained which explained 64% of the variance (Table 2). The factors did not contain balanced numbers of items, and rotation did not assist interpretation, so unrotated results are presented. These factors produced a result somewhat more complex than expected from the four components of the original index (three exacerbation scenarios and general preferences). One factor, explaining 47% of the common variance, consisted of items from the stable disease and the severe exacerbation scenario, plus 4 of the general preference items. It could be argued that these items would be consistent with predominantly PS-type issues as defined by Deber et al. (10) Another factor consisted of items from the mild attack scenario, along with two general scale items concerning decisions about 'everyday problems', and the 'need for a check-up'. These are predominantly DM-type items by Deber's analysis. These items are associated and form a domain that could be described as 'action plan decisions'. This factor explained 17% of the common variance.

In order to ascertain whether there remained an interpretable overall autonomy preference factor that affected all types of decision-making preferences, a hierarchical factor analysis was performed. This value of this

process has been elaborated by Wherry. (32) In this strategy clusters of items are identified and then axes rotated through these factors. Correlations between those oblique factors are computed, and then the correlation matrix is further factor analysed to yield a set of orthogonal factors that divide the variability in the items into that due to shared or common variance (secondary factors), and unique variance due to the clusters of similar variables (items) in the analysis (primary factors). Factor loadings derived using this process demonstrated the presence of an overall (secondary) factor that likely affects all self-management autonomy preferences, in different situations and in general, in addition to the two primary factors.

API Scores

The mean scores for each exacerbation scenario, general items and for the overall preference index, are shown in Table 3. With the exception of the mild exacerbation scenario, patients on average showed a preference for at least shared or joint decision making with regard to their asthma, with a tendency to prefer clinicians to assume the major role in decision-making. The mean scores were greater than 3 for each situation at both hospitals, apart from the mild exacerbation (a score of 5 indicating the doctor alone should make decisions, and 1 indicating the patient alone should do so). For total autonomy, 37% scored less than 3, indicating a preference for greater input than their physicians into treatment decisions.

The mild exacerbation scenario concerns preferences for autonomous decision-making in a situation corresponding to that covered by most written asthma action plans. This scenario requires a patient to make decisions regarding initiating changes in medications in response to increased symptoms. In this situation patients expressed significantly stronger preferences for self-management autonomy than during a routine visit for stable disease or for during an attack requiring admission to hospital ($p < .001$ for all comparisons). This was despite a large proportion (45%) reporting not having a written asthma action plan, and for preferences to be only weakly

correlated with possessing a written plan, (r = 0.18), and with length of history of asthma (r = 0.17). Sixty-four percent of subjects scored lower than 3 for the mild exacerbation, indicating a desire to be responsible for decision-making during an attack which would require increased medication but not an admission to hospital.

During a severe exacerbation requiring hospitalisation, scores were significantly higher than for either of the other two scenarios ($p < .0001$ for all comparisons), indicating weaker preferences for autonomy during a more severe episode. However, 26% scored below 3, indicating equal or greater participation in decision making during even a severe attack necessitating admission to an intensive care unit.

For all scales except the mild attack scenario, TQEH patients expressed less desire for decision-making autonomy than subjects from the LMHS (Table 4). However, when items were analysed individually, only on 8 out of the 18 questions were there significant differences in scores between the two hospitals. These were the four items from the stable disease scenario, and 2 items from the general scale, dealing with everyday problems and check-up frequency. On the issue of when to start prednisolone in an attack, TQEH patients expressed a significantly greater desire for control than LMHS subjects. For the other 3 items in the mild attack exacerbation scenario there were no differences between hospitals. Thus for the decision-making or 'action-plan' factor there was no difference between the two hospitals. For the problem-solving factor, the LMHS subjects reported stronger autonomy preferences. This was particularly for those items where the clinician is offering advice, as in the routine ambulatory review about such things as the next visit. Thus, the differences between hospitals were largely due to differences about seeking medical help or taking advice, rather than taking self-initiated action in asthma attacks.

Examining the pattern of responses for each of the items, there were 3 questions which scored significantly lower than any of the other items

(indicating higher autonomy preferences). These were the items asking about 'whether you should be seen by the doctor?'; and whether 'you should feel free to make decisions about everyday problems with asthma?'; and who 'should decide how frequently you need a check-up for asthma?' (Table 5). These items concern decisions regarding the timing and frequency of seeking medical care. Scores for the item concerning 'as your asthma became worse you would want your doctor to take greater control', (Q17), indicated significantly less desire for autonomy in this situation than for other items ($p = .02$).

Responses between the three scenarios and with general preferences were all significantly correlated at the $p < 0.00001$ level (Table 6). There were no significant differences in responses between the combined scenarios and the general scale.

As the factor analysis indicated an "action plan" decision-making domain, scores were calculated for the combined items (Q5-Q8, Q16, Q18). These showed a tendency for patients to express a desire to retain control over decisions in this domain of self-management autonomy. As discussed above, the "action plan" group of questions deal with the mild attack situation, plus deciding when to seek out medical help as a general principle. Scores did not differ significantly between the two hospitals.

Change in Autonomy Preference Index scores over 12 months.

The index was presented to all subjects at 12 months following the completion of the survey at baseline. A total of 78% completed the questionnaire one year after baseline. Results from this are given in Table 7. Autonomy scores of those with both baseline and follow-up scores did not differ significantly from those with baseline scores only ($p= .32$), and standard deviations were also highly similar suggesting similar distributions.

No significant changes were seen at 12 months from baseline for any of the scenarios, general preferences or the overall index scores at either TQEH or LMHS. There were no differences found between the two hospitals in change scores for any aspect of the index. All effect sizes measured by either method returned values less than 0.2, which is by convention the minimum level at which any effect is said to be appreciable. (29,31) Change scores showed no associations with any other measured variables. Overall, it can be seen that the index scores showed no real change over the 12 months from baseline.

Univariate Associations

Univariate correlations with a number of psychological, attitudinal, clinical and socio-demographic variables are shown (Table 8). In addition whether a patient reported having a written asthma action plan was significantly associated with scores for the mild exacerbation scenario (r = .23). There were no significant associations with any of the attack scenarios, or for the overall index, with any of the symptom scores, dose or number of asthma medications, lung function as measured in clinic, previous admissions to hospital or emergency service visits for asthma, length of asthma history, days absent or affected by asthma in the past 12 months or quality of life as measured by the SF-36 and the modified Marks Asthma quality of life questionnaire. Of the psychological and attitudinal variables, there were no associations seen with the value placed on health, dislike of asthma medications, avoidance coping, denial, or self-reported medication adherence. With regard to socio-demographic factors, autonomy preferences were not associated with gender, marital status, gross income or main source of income, housing situation, country of birth, level of social support, concerns about missing work delaying seeking care, or private insurance status. There were also no associations with specific attitudes or beliefs about asthma medications, such as perceived effectiveness of medications, knowledge regarding appropriate use of medication, belief in the efficacy of alternative medicine or technical skills in inhaler use.

Stronger preferences for decision-making were associated with more education, more concerns about side-effects, use of more active coping strategies, a more positive evaluation of having asthma, greater self-efficacy in asthma management, and a physician who tended to involve patients in treatment more. Younger patients also expressed a greater desire for self-management autonomy.

Multivariate models of decision-making preferences

Linear regression

The autonomy index scores formed a continuous distribution which was normally distributed (Shapiro-Wilk $p > .05$). The number of cases or observations was greater than twenty times the number of independent variables entered, which was adequate for regression analysis. Forward stepwise multiple linear regression was performed to identify which independent variables contributed a significant amount of variance. From the correlation matrix, variables significant at the $p < .10$ level were retained for analysis and entry into a forward stepwise regression analysis. All of the variables that were entered into the analysis included those, which on the basis of previous reports in the literature or by intuitive sense, would be likely to be predictive of autonomy preference scores. These included age, education level, concerns regarding medication side effects, confidence or self-efficacy in self-management, and the doctor's attitude to this process. As the PDM style, which was only measured at the 12-month follow-up, was hypothesised to be an important predictive variable of autonomy preferences, the analysis was performed on the 12-month follow-up data. This was felt reasonable given the stability of the sample, and of the measures over this period.

The results show that greater concerns regarding medication side effects, a higher education level, a doctor who encourages participation in decision-

making, a greater degree of confidence in managing asthma, and using more active, problem-solving strategies predicted a stronger desire for autonomy in decision-making with regard to asthma management (Table 9). Concerns about costs causing delays in seeking medical care also showed association but this did not reach statistical significance at conventional levels ($p = .06$). When age was forced into the model to allow for its independent effect as another potential predictor, it did not improve the goodness of fit and removing it from the final model did not affect the results. Analysis of the correlation matrix, semi-partial r-values and tolerances of the variables entered into the model did not suggest the model was affected by multicolinearity or that the matrix was ill conditioned. Analysis of the residual plot against fitted values revealed no pattern of points, suggesting the linear model was consistent with the data. The model was able to explain 38% of the variance.

Responses to the mild attack scenario were not entirely consistent with prior expectations in that Gibson et al had previously shown scores tending to favour less desire for autonomy in attacks compared to the stable disease situation.(7) To investigate whether different independent variables predicted preferences in mild attacks compared to the overall autonomy index, models were developed for the mild attack scenario, and for the rest of the index scores without the scores from the mild exacerbation included. This could be useful for generating hypotheses for further research utilising the Autonomy preference index. It may also assist in understanding patient attitudes and behaviour in this scenario, which corresponds most closely in real-life with the situation in which asthma action plans are supposed to be used by patients.

The model for the Index minus the mild attack scores was not significantly altered from the original overall model. It contained the same variables with similar levels of statistical significance. Autonomy preference in mild attacks could be predicted by an active, problem-solving coping style, medication side-effect concerns, doctor's participatory style, and confidence/self-efficacy in managing asthma. Again, concerns about costs causing delays in seeking

medical care also showed association but this did not reach statistical significance at conventional levels (p = .068). Education level was not significantly associated with preferences for control in an acute exacerbation. This model could explain 32% of the variance. Possession of a written action plan, length of asthma history, general hospital admissions or admissions to the intensive care unit over the past 5 years did not contribute to explanation of the variance and were not retained in the model.

Logistic regression

Although a linear structure model appeared valid and useful in predicting variance of autonomy, multiple logistic regression models were performed for the dichotomous outcome variable of autonomy score above and below the mid-point of the index (ie score of 3). That is, for those who favour the doctor to make decisions, and those who favour the patient to do so. A forward stepwise regression was done, with $p<0.05$ to enter the model, and $p> 0.10$ for removal of variables. Education was classified as more or less than 3 years of secondary education. Social support was converted to a dichotomous variable with a cut-point of 7 on the scale. Concerns about side effects was recoded as positive for frequently or most of the time preventing from taking asthma medication. Doctors style was recoded as a dichotomous variable with a cut-point of 7 on this scale. Confidence and active coping were recoded with the cut-point at the median value for each scale.

Total API could be predicted by multiple logistic regression from medication side-effect concerns (concerns about side effects frequently or most of the time prevent from taking asthma medication); education level (> 3 years secondary education); confidence in managing asthma, higher social support, and a higher physician's participatory decision-making style. (Table 10). Active coping strategies remained within the model (p = .08). Age did not improve the goodness of fit. Odds ratios adjusted for age, gender and employment status of the household are also presented. These were not significantly different from the unadjusted values. The goodness of fit was

evaluated by deviance analysis and by the Hosmer-Lemeshow test. (33) A non-significant chi-square value, as found in this model, indicates that the probabilities predicted by the model do not differ significantly from the actual results.

A logistic regression model was also developed for autonomy preferences in the mild attack scenario (Table 11). Confidence/self-efficacy with asthma management, physician's participatory style, an active coping style, and concerns about costs causing delays in seeking care, were significant predictors of preferences. Medication side-effect concerns contributed to the model with a p-value of 0.082. Goodness of fit statistics suggested the model was appropriate for the data.

Although some variation in significance levels was seen, the linear and logistic regression techniques produced very similar results for both the API overall and for the mild attack exacerbation. The main difference between the overall scale and the hypothetical attack scenario was that education level was not a predictive variable in the mild attack. However, delaying seeking needed care due to worries about the cost implications of this action was a predictor of attitudes to decision-making in the attack scenario.

Participatory Decision-Making Style.

A summary of the PDM style and Patient Satisfaction scores are shown in Table 12. Possible aggregate scores for PDM ranged from 3 to 15, with higher scores indicating less participatory visits. Internal consistency reliability, measured with Cronbach's Alpha, was 0.80, which compares with a value of 0.74 in the original reports of Kaplan et al. (18,19) The average inter-item correlation was 0.58. Mean scores for the measure and for each of the 3 questions were below the mid-point of 3, suggesting patients' felt that on average their physicians would be more likely than not to involve them in decisions. Although age was related to PDM, this relationship was not linear, with those aged less than 40 years having significantly less participatory visits

than all other age groups. Those aged between 41 and 50 years had significantly more participatory visits than those in older age groups. Females reported more participatory visits than males but this just failed to reach statistical significance at conventional levels ($p = 0.58$). Education was related to PDM style; those with less than 3 years of secondary education had less participatory visits than patients in the other educational groups (Table 13). Marital status or country of birth did not affect PDM style, but as few patients were born in non-English speaking countries this result needs to be interpreted with caution.

PDM style showed a relationship with patients' global ratings of their health status (Table 13). Those rating their health as "excellent" had significantly more participatory visits than those rating their health as "very good, good or fair". Subjects reporting their health as poor had significantly less participatory visits than those in other categories. There were no statistically significant differences in PDM style for patients who rated their health as "very good" versus "good" or versus "fair".

Both the duration of the clinic visit time in minutes spent with the physician and the tenure of the physician-patient relationship showed statistically significant relationships with PDM style (Table 12). Clinic visits which lasted less than 5 minutes were significantly less participatory than those lasting between 6 and 20 minutes. Those lasting longer than 20 minutes were even more participatory than all shorter visits. Those with less than a 6-month relationship with the particular doctor they saw in the clinic had less participatory visits than those with a longer tenure of relationship. There was no relationship between PDM style and how long a patient had been attending the hospital clinic, as distinct from a particular doctor in the clinic. Middle-aged (41-50 years) subjects had longer visits than either older or younger patients.

PDM style was significantly correlated with visit length ($r = .33$), tenure or relationship with their doctor ($r = .30$), educational level ($r = .45$), age ($r = .37$),

and patient satisfaction with interpersonal care (r = .30). Patient satisfaction was not related to the other variables measured, indicating that PDM style and satisfaction with care are conceptually distinct.

Dummy variables were used in the logistic regression model for categorical variables. PDM style could be predicted using logistic regression from the length of the office visit (> 20 minutes) and the duration of tenure of the physician-patient relationship (> 6 months). (Table 14) The effects of age did not remain significant when length of visit and duration of tenure were included in the model. The effect of education was confounded, both by age and visit length, and did not remain in the model when these other variables were included. Including perceived health status in the model did not alter the significant effects of visit length and length of provider relationship. Patient satisfaction, gender and tenure of hospital-patient relationship did not contribute to the model.

Discussion

Autonomy

One goal of this part of the study was to confirm the validity and reliability of the Autonomy Preference Index for use in Australian asthma patients. Although its use has been described previously in subjects with asthma, validity data was not included in the report by Gibson et al. (7,7) Both internal reliability and test-retest methods showed remarkable consistency for the exacerbation scenarios and the general attitudes to autonomy components of the index. It is of note that the mean inter-item correlations are considerably lower than the alpha values. This relatively modest agreement between items seen here despite reasonably high alpha values has been reported previously for a number of scales, including the SF-36 Health Survey. (35) These values are slightly higher than those reported in the original paper by Ende et al in general medical patients. (8) Testing of concurrent validity also confirmed its utility, with a moderately strong correlation with a global item of autonomy.

The ability of the API to predict future health is discussed in Chapter 9. Thus the autonomy preference index has acceptable reliability for use in adult asthma patients.

Deber and colleagues asserted that 6 of the 18 items from the original API (8) related specifically to decision-making, with the other 12 including large problem-solving components in their constructs. This was based on decision-analytic grounds, and factor analysis or other statistical analyses were not provided. (10) The results of the factor analysis gave some support to this thesis. One factor consisted of items that would arguably be 'problem-solving' in decision analytic parlance. These items, at least in part, involve identifying possible alternatives and the best therapeutic options, are felt to be best left to those with expertise, ie the clinicians, with generally less role for patient involvement. For these, patients tended to favour deferring decision-making to medical staff. This was particularly the case for items concerning the hypothetical severe attack requiring admission to the intensive care unit. The second factor contained items regarding the decision to obtain help, and when and what medication changes are appropriate during a typical asthma attack. As such, they correspond to the usual situation faced by asthma patients when symptoms are increasing, ie what should be done now, and when to seek medical assistance. These are predominantly 'decision-making' issues according to Deber. (10) The attitudes to these two domains differed, with patients preferring greater involvement with decisions in the 'action plan' domain than in the problem-solving/identification area. Patients feel decisions regarding about when to seek medical care should remain in their domain. The decisions about when and what treatment should be initiated in a moderate asthma attack are felt to a shared process, with approximately equal input from clinicians and patients.

The factor analysis also confirmed that meaningful analysis could be made on the index overall. The high inter-item correlations and other reliability data suggest the results are internally consistent across and within patients, and that the attitudes to the PS and DM/action plan-type items are related.

The results of this study generally support those of Gibson and colleagues (7), and suggest that, on average, persons' with asthma do not desire to be solely responsible for decisions regarding asthma management. The data helps to clarify the nature of autonomy preferences in asthma patients. Decisions requiring a higher level of specialised knowledge are felt to be appropriately left to doctors, with options then communicated to patients. This is particularly so in severe illness where emotional dependency on doctors can be expected to be higher than in less personally dangerous situations. (3) Where patients did wish to remain in control was in choosing when to come and see a doctor about their asthma. This was so for routine "everyday problems", and for "check-ups", as well as during an acute symptomatic episode. A pattern emerges where patients regard medication changes to be a negotiable issue to be decided together with the doctor, and would not initiate these changes without consultation, but that the decision to initiate the process of consultation by seeking medical assistance remains with the patient. This is so regardless of whether the patient has been provided with a written asthma action plan. There is clearly some tension in these two viewpoints. Whilst not surprising in itself, it has important implications for the use of action plans as a major tool of asthma self-management. It implies that to address the problem of delays in initiating appropriate changes in care in acute attacks two separate but conceptually related areas of decision-making must be considered. Merely providing a written plan will not necessarily assist patients to initiate changes in acute attacks, unless the question of when to seek help has been specifically negotiated as well. The alternative is that the points during an attack which trigger action are fairly precisely specified and patients understand, agree and "sign off" on them. It may mean that the standard action plans currently in use will not be appropriate for all patients. The clinician may need to decide, in negotiation with the patient, whether to emphasise the appropriate time to seek help as the major aspect of self-management, or to concentrate on appropriate initiation of medication changes in response to an attack.

Becker and colleagues have indicated the difficulties individuals face in deciding when to seek medical assistance for acute asthma episodes. (36) They and others point to the unpredictability of an attack, and how patients are torn between a desire to manage by themselves and remain "normal" (37), and to get the best possible care. The balancing of risks, to avoid the negative experiences sometimes associated with being discounted or ignored in emergency departments, is weighted against previous experiences of how attacks develop. (38) Identifying which patients are more likely to respond in either direction becomes important; and this data goes some way towards doing this, as discussed below.

A second goal of the study was to provide some insight into what factors might be associated with the autonomy preferences. The results suggest a complex interplay between an individual's psychological make-up and personal experience both of life and of asthma, and the attitude and approach of the responsible clinicians. With regard to emotional and psychological variables, univariate analyses suggested a role for coping styles, the degree of confidence / competence in managing attacks a person has, and the level of positive evaluations or satisfaction a patient has with having asthma. Added to concerns about medication side-effects that lead to stopping medications, which may be a reflection of previous experiences or acquired from other sources, these variables suggest how comfortable someone is with their asthma and its treatment will affect the level of desire for keeping control over decisions.

Socio-economic factors play a role as well. The impact of formal education mediating this relationship is clear. When education is taken into account, the effect of age on autonomy preferences disappears. Education was a significant independent explanatory variable in the study by Ende et al (8), but had not been examined in asthma patients before this. Other socio-economic factors, particularly cost concerns were significantly related in univariate and multivariate analyses. As other authors have reported, it would seem unlikely that patients will enthusiastically initiate increases in medications or seek

medical advice if the cost implications of these actions weigh heavily in their assessments. (39) Attempts to promote self-management without directly addressing these issues may prove futile. Cost concerns were particularly an issue in the exacerbation scenario, emphasising the powerful influence economic circumstances exert over behaviour and attitudes in what may be regarded by clinicians as a relatively straightforward medical situation. This variable remained significant even when adjusted for employment status, which from the literature is the most consistent social factor predicting patient distress and greater use of emergency services. (40) Given the nature of the questions asked in this scenario, which concern altering medication, it is possible these items may for some people be just inquiries of their ability to afford the cost of the medicine.

The regression analyses confirmed the importance of worries about side effects, education and the clinicians' style of management, in predicting autonomy preferences. An active coping style, which is task oriented, and directed towards solving any problems experienced with asthma by actively seeking information from others was also predictive. Confidence or a sense of mastery, over asthma and its management was a further predictive variable. Individuals who cope with stresses by seeking out information, formulating plans and viewing these stresses as challenges to be overcome could be expected to want to retain some control over treatment decisions. Individuals, who actively question doctors, express opinions and seek out information and solutions to problems, have been found to have better health outcomes in other illnesses. (11-13) Interventions which teach the necessary skills and encourage patients to negotiate treatment decisions with their doctor show improved outcomes. (12,41) An increased sense of personal control leading to the confidence and the desire to manage their treatment may be one mechanism via which these interventions are effective.

That side-effect concerns have an important bearing on how a person feels about control over treatment seems reasonable. Individuals who expressed strong concerns about side effects also said that these concerns stop them

taking many asthma medications. What is unclear from this study is whether greater concerns, leading to stronger autonomy preferences, would actually make someone less likely to initiate medication changes in exacerbations. This would clearly be at odds with the intention of the guided self-management philosophy of using action plans for attack management. It also suggests a strong focus of education programs needs to be on addressing concerns regarding side effects of medications. The data does not show whether the concerns held by people were erroneous or unwarranted fears, or if they arose out of previous adverse experiences. Chapman has indicated that negative attitudes regarding childhood immunisation often stem from deeply held suspicions of the motives of government, pharmaceutical companies and the medical profession. As such, they are not easily amenable to change by simply laying out what doctors might see as the 'facts'. (42) From the perspective of pragmatically attempting to enhance appropriate self-management in exacerbations, whether these fears are unwarranted or not is less important than the realisation by clinicians that real fears exist and have a major influence on attitudes and behaviour in asthma management. It would therefore seem important to engage with asthma subjects in exploring these concerns.

Confidence in managing asthma was a significant part of the model. This is consistent with the view that those who feel more competent to deal with an attack will feel greater desire to initiate changes in management. We could expect this to be related to the length of asthma history, or possession of a formal, written action plan, but this did not prove to be the case. An increased sense of control and mastery over the circumstances of asthma is likely to increase the desire to control treatment decision-making. Whether a formal education program which could improve self-efficacy (43), and consequently self-management autonomy, cannot be determined from this data.

Defining social support is difficult (44); the index used here measures perceptions of both personal support and social networks available to the

individual, and provides a broad measure of social support. The degree of available social support will have a significant influence on the attitudes patients have towards any management regimen that requires their cooperation or a change in their lifestyle. (40) In particular, the effect of those close to the patient on giving 'sanction' as to when seeking help is appropriate may be a critical influence on how patients' report on their autonomy preferences, and on how they behave with regard to asthma self-management. (44) This would apply to those who may have had previous adverse experiences with asthma attacks or in taking certain asthma medications, as well as persons with recently diagnosed asthma who may lack the experience to feel confident asserting their rights to decision-making. Rael and co-workers reported from the Whitehall II study that high levels of emotional support may encourage illness behaviour and work absence, but that negative aspects of close relationships may jeopardise health and hence also resulted in higher rates of sickness absence. (45) The socially isolated may be less likely to have the confidence to initiate actions without the direction of the physician at the time. What is unclear from the data is the extent others depend on the subject and the influence this has on reported autonomy preferences. It is unlikely those who are relied upon by others will relinquish much decision-making autonomy, but the direction self-management takes in these circumstances is problematic. Parents, or family "breadwinners", may be less likely to initiate early treatment if it involves missing work or if childcare were to be jeopardised. Including a measure of dependency in future research, along with an assessment of negative aspects of social support, would provide useful information on the influence of social interactions on asthma health attitudes and behaviour.

The independent effect of the clinicians' participatory decision-making style is consistent with other research showing the importance of the doctor-patient relationship on patient adherence and behaviour in asthma. (39,46,47) This effect was seen independent of such factors as possession of a written action plan, inhaler technique, knowledge of what to do in an attack, length of history of asthma or satisfaction with care. This suggests a critical role for how that

material is expressed and the attitude of the doctor in involving the patient, in fostering decision-making independence. The results of the PDM style measure show that the patient's perception of their doctor's approach to involving them in decision-making is directly related to the length of the consultation and the absence of provider switching in the clinic. This issue is discussed in more detail below.

No evidence was found to support the contention that clinical severity or quality of life was related to autonomy preferences. The notion that those with higher autonomy would have less morbidity and higher quality of life was not supported by the cross-sectional data. Marks et al have reported that patients' who have frequent symptoms are more likely to alter their own treatment in an attack without first consulting a doctor. Although subjects in their study who had worse quality of life were more likely to have oral steroids at home, they were not significantly more likely than other patients to start taking them on their own initiative. (48) Duration of symptoms has been reported to be associated with the likelihood of patients' contacting their general practitioner, independent of patient perception of the severity of the symptoms. (40) Length of symptoms, as distinct from frequency or severity, was not a variable in the data-set, although length of history of asthma was not associated with autonomy preferences.

Although, the data here has advanced our knowledge of what contributes to patient preferences, most of the difference among patients is contained within individual characteristics that were not captured even by the extensive range of variables measured. Ryan has written in relation to illness in general, that patients' construction of illness is "usually complex, pragmatic, and seldom produced for critical public analysis". (37) This study adds to the relatively small, but growing literature of how people view their asthma. (38)

The TQEH subjects reported lower preferences than LMHS patients in the PS-type items, but equal or stronger preferences for DM/Action plan items. The data allows us only to speculate on why this may be so. It is possible

that the greater involvement of specialist respiratory physicians, with possibly greater expertise and interest in asthma, and a stronger commitment to the concept of using asthma action plans, has encouraged TQEH patients to feel more comfortable or aware of actions to take in a mild/moderate asthma attack. Given the attitudes of patients on other items, this approach may not translate as decisively to other areas of asthma management

Autonomy preferences remained unchanged on average over a 12-month period. Any small movements were toward expressing less strong desires for control over decisions. These did not reach statistical significance, nor did these changes constitute a large enough effect size to be considered significant at convention levels. No measure is available to determine what is the minimally important clinical difference in autonomy preferences, and none was specifically constructed for this study. It is unlikely that a clinically meaningful change would be seen in the absence of statistically significant changes over time in mean scores or effect sizes. (49) The index was shown to be a stable measure of preferences over time across both hospitals and for different scenarios. The gradient seen in the scenarios for differing severity of disease was maintained. Thus, while preferences are dynamic across an exacerbation as it becomes more severe, the passage of time alone does not necessarily lead to changes in attitudes. The only scenario in which the change in scores approached statistical significance was the mild attack. This is the situation, which corresponds to that covered by written action plans. As such, managing clinicians may have invested more effort on fostering self-management autonomy in this area. That this did not show significant effects emphasises that this is not a simple or trivial task. It may be that in the absence of a specific intervention directed at changing autonomy preferences there is unlikely to be any change in attitudes. The frequency of attendance for all medical encounters was not recorded for this study, so that the cumulative effect of usual clinical visits on autonomy preferences is unknown. It is of note that length of time since diagnosis of asthma was not related to autonomy preferences.

The API is a sufficiently stable instrument such that any changes in scores above approximately 0.2 would be statistically significant. An alternative interpretation of these results is that the API is insufficiently sensitive to anything but very large real changes in autonomy preferences and would not be a useful measure of autonomy in an intervention. It could be argued that as no significant changes were seen in clinical status or quality of life over time (see Chapter 4), then if autonomy were related to these outcomes, the absence of significant changes in autonomy is being reflected in the stable clinical condition of the patients. Alternatively, as autonomy was not associated with quality of life in cross-sectional analysis, no longitudinal relationship can be assumed. It may be that any effect of preferences for decision-making autonomy on quality of life or clinical status is exerted over a longer period of time than the 12 month follow-up made on the study patients, and hence would not expect to have been seen here.

Whether such changes would be clinically meaningful would be dependent on seeing a relation between attitudes and behaviour. The association between API scores in this sample and clinical outcomes such as hospital admissions, and quality of life changes over time are presented in Chapters 5 & 9. Clearly, other factors are of critical importance in influencing these outcomes. To fully evaluate the direct impact of attitudes on behaviour would require individual interviews of patients during exacerbations to determine the appropriateness of any action they may have taken. (39) Objective measures of medication adherence would be needed to better evaluate the connection between autonomy preferences and self-management behaviours in stable disease.

In summary, the API is a valid, reliable measure of patient's preferences for decision-making in asthma patients. It would appear that the amendments made for its use in asthma have altered its psychometric properties. (7) The analysis of the factor structure suggests two domains concerning predominantly decision-making and problem-solving, respectively. The problem-solving domain deals with decision-making in a situation of major

importance in asthma self-management, ie that of seeking help in an attack and when to initiate changes in medications. These domains are related and form an overall Asthma Autonomy Preference Index. In general, patients prefer joint decision-making in managing their asthma. The decision to initiate contact with health services is felt by patients to be predominantly their prerogative. A number of variables, which can predict patient's preferences, have been identified. In asthma self-management the issue of patient autonomy in decision-making will need to be directly addressed. To promote patient autonomy both individuals' attitudes and the doctor's approach will be important.

Participatory Decision Making Style

To the extent that patient satisfaction is a marker of the quality of interpersonal care, then PDM style has been shown to be a valid indicator of care quality. Its strong association with other variables that can be expected to predict better quality of care further supports this, ie longer office visits and a longer relationship with an individual physician. Although this measure is based on patient-report only and not on direct observation of the doctor-patient interaction, previous reports have shown a significant correlation between the 3-item measure and a measure based on direct observation of consultations. (19) Previous authors have indicated that patients tend to rely more on the physician's communication style than on the specifics of treatment when evaluating medical care. (50,51)

PDM style was found to be associated with patients' age, educational level, and perceived health status. This is similar to the findings of Kaplan and co-workers in their original report in a sample with a number of different conditions. (18,19) Specifically, middle-aged individuals had more participatory visits, and spent a longer time with the doctor in clinic. These findings are consistent with previous work that has shown that physicians are less likely to spend time with, provide less information and be more conversationally controlling with both younger and elderly patients. (18,19,52) The behaviour of the patient may also be important in demanding a more interactive style of consultation. In this, the elderly have been shown to engage in less of the conversational behaviours (asking questions, asserting opinions) that would prompt responses from doctors. (18,53) The interaction between age and length of clinic visits, with the middle-aged having longer visits, suggests a probable interaction between patient behaviour in the consultation and both the doctor's inclinations and responses to the patient.

Although females reported more participatory visits than males, this just failed to reach statistical significance. The absence of a significant relationship with gender as was reported by Kaplan et al, may be a reflection of the much

smaller sample size here and the nature of the sample, with significantly more females than males. (18) The effects of age or education level did not significantly confound this relationship.

PDM style of the doctors' also varied with patients' educational level, at least for those with low levels of formal education. This relationship was complicated by patient age, as the more elderly subjects had, in general, less education than younger patients. This raises the question of whether the physicians' vary their style in response to their perception of the patients' interest in and ability to participate in decision-making. The interaction with length of office visits also suggests this possibility. Other authors have noted that those with less education can respond to interventions designed to increase participation in care. (11) Whether a simple increase in the amount of time spent with the patient can increase both the doctors' PDM style, patient autonomy, and subsequently patient outcomes, merits further research.

Organisational characteristics of the office visit (length of the visit, and length of tenure with a particular physician) were found to be the most important factor in promoting a more participatory style from doctors. The length of time the patient had been attending the clinic was not related to PDM style, suggesting a negative effect of provider switching within the clinic, where patients' see a different doctor at successive visits. This is consistent with previous work that has shown the importance of continuity of care on outcomes. (54,55) One policy implication of this result is that returning to the same clinic is not the same as returning to the same doctor, and does not automatically constitute continuity of care, at least in terms of promoting participation in decision-making, with possible effects on health outcomes.

It could be argued that these results represent selection effects: the longer the relationship between a doctor and patient, the more likely interaction and participation will occur. However, as Kaplan et al have noted, given the effects remain despite adjustment for age, education and gender, then this

characteristic would have to be independent of, or substantially confounded by, these variables. (18) An alternative hypothesis, that PDM style promotes more stable relationships between patient and doctor, would not necessarily apply in outpatients of public hospitals, where patients are often "slotted in" at the convenience of the clinic rather than the patient. It is also possible that as the doctor sees the patient more times they become more confident in the patient's ability to have greater control over treatment decisions.

The results show that visits of greater than 20 minutes are needed to achieve high levels of PDM. The actual length of clinic visits was not measured in this study. It is possible that patients' perceived the visit to be longer if the doctor was more engaged in promoting their participation in treatment decisions. These results may be a 'halo effect', merely a reflection of the "nice physicians with more time". (56) There is therefore the risk of confounding the physician's actual style with the patient's perception of the amount of time spent with the doctor. However, other work has demonstrated similar findings based on direct observation of office visit length, supporting the basic finding of this result. (15,18)

The cross-sectional nature of the PDM style part of the study limits the ability to assert causal links between visit characteristics and PDM style. It also limits the ability to draw similar conclusions regarding health outcomes and PDM style. It is possible that those who report better current health have more positive views of their doctors and more favourable interpretations of their participatory behaviour. However, the large difference in reported PDM style between those with excellent health and the subjects with poor health is consistent with previous work. (11-13,18)

The characteristics (eg age, gender, race, years since graduation) of clinicians was not measured in this study, as patients were not asked to identify which individual physician they attended. Kaplan and colleagues found differences in PDM style according to some of these clinician demographic variables. (19) Future work would need to examine the effect of

these characteristics on PDM style related to asthma in expanded numbers of physicians.

Kaplan et al found an association with PDM-style and physician age, race and gender (19). As subjects in this study were not required to identify their treating physician this data is not available here. It is likely demographic characteristics of clinicians will affect their PDM-style. Future work could examine this relationship in a variety of clinical settings such as primary care practice and in different specialty groups, in asthma patients of varying severity.

Autonomy, Physician behaviour and Asthma Self-management.

Pratt has argued that health care is a problem-solving endeavour requiring active coping rather than passivity, and that the doctor-patient relationship is a system of social behaviour that can be entered into to negotiate for services. (57) This implies a concept of reciprocity in the medical encounter (58), which places the exchange of information within the context of an exchange of rights and obligations. Roter and Hall have elaborated this notion of reciprocity to suggest both patient and physician behaviours have task-focused and socio-emotional realms that reciprocate each other. (58) These involve information sharing and gathering as well as counselling on the part of the physician, and accurate and full reporting of problems and an active participation in the care process by patients. Their work indicates that information achieves its therapeutic effects both by its explicit content and the interpreted message of interest and caring. (58) Compared with friendliness or question-asking, task-oriented communications and information-giving from physicians were more likely to evoke reciprocal task-relevant responses from patients. (58)

A large component of health care is intangible, involving affective exchanges between people, and with emotions intimately linked to outcomes. A consumerist view of health-care needs to acknowledge this high level of

emotional investment in order to understand what 'consumers' of health want to achieve. (3) An individual's response style to illness will be constructed dynamically with experiences that accumulate over time. Responses that stress both personal autonomy and passive 'dependence' may be viewed as rational in different circumstances. (3) In a context where uncertainty is inevitable, the beneficial effects of the doctor-patient relationship providing comfort and unburdening the individual from the need to make all the decisions is potentially important. (59) It has been suggested that 'satisfaction' with medical care may reflect a desire to be dependent on a paternalistic doctor, confounding expectations regarding consumerism. (60)

The results of this study have shown that patient satisfaction with care is correlated with the propensity of the physician to involve them in making decisions about their care. This, in turn, is related to the desire for patients' to be more autonomous in management decisions. Crucial aspects of this process may be allowing sufficient time, both in individual consultations and over their therapeutic relationship, for both the patient and physician to develop the trust and the inclination to embark on sharing management. Confirmation of this in studies that directly measure clinic visit length is important for future policy. The potential importance of this is seen in the relationship between self-reported health status and PDM style. Trust, confidence, and empathy with the doctor may also be of practical importance in addressing the issue of side-effect concerns, which is the major potentially remediable factor relating to decision-making autonomy preferences. Encouraging patients to negotiate treatment decisions with their doctors, which may be seen as promoting an 'active' coping style, has been achieved in other illnesses with relatively simple interventions in the clinic. (12,13) While this particular approach may not be easily implemented in the community setting, initial 'proof of concept' of its worth in high risk patients would potentially be cost-effective. More widespread use of this approach using the burgeoning Web-based communications industry is a future possibility.

However, this still ignores half of the patient-physician dyad. Physicians' who hold more positive beliefs about the psychosocial aspects of care have more psychosocial discussions with patients and appear more involved as partners in care with patients. (61) Intervening to change physician attitudes and behaviour may augment the effects of patient-directed interventions. (15) Communication-skills training focusing on emotional aspects can reduce emotional distress (62,63), but not necessarily other health outcomes. (62) Changes in patient outcomes have been seen after interventions designed to alter doctors' behaviour. (64) One potential means of achieving this may be to adapt the concept of the "patient partner program", to asthma. Using patients with arthritis as trained educators has been shown to improve medical students' skills in musculo-skeletal examination. (65) The use of trained patient educators to provide peer education and support has also been reported to increase patient satisfaction and knowledge of arthritis patients. (66) In asthma, similar approaches could be used to emphasise to students and clinicians the concerns patients' have with the use of regular long-term medication use, both with side-effect worries and in terms of adapting their lifestyles to using them. This would promote the kind of task-oriented communication shown to be associated with increased patient satisfaction and better outcomes in other conditions. (58) The issues that effect attitudes to autonomy preferences could be made more apparent to students and clinicians, and could be openly discussed between patients as well.

To conclude, there seems little reason to suppose that an extreme consumerist position, undermining professional claims to expertise, is favoured by many asthma patients. It does seem clear, however, that many people favour medical interactions in asthma where options are presented to them and the decisions are then made in conjunction with the doctor. It would appear that an approach that deals with self-management individually is the preferred option for most patients and has the most chance of success. The difficulty is that this will be demanding of both the time and the emotional and clinical resources of the attending physicians.

Table 1: Reliability and Item Analysis.

	Cronbach's Alpha	Ave. inter-item correlation
Scenarios (Q1-12)	.84	.42
General (Q13-18)	.82	.43
Total Autonomy (Q1-18)	.87	.40
"Action plan"	.82	.46

Test-retest repeatability

	Intra-class correlation
Scenarios (Q1-Q12)	.89
General (Q13-Q18)	.92
Total autonomy (Q1-Q18)	.91

Item-total correlations

	Item-total correlation		Item-total correlation
Q01	.52	Q10	.46
Q02	.48	Q11	.60
Q03	.59	Q12	.47
Q04	.52	Q13	.57
Q05	.22	Q14	.51
Q06	.47	Q15	.51
Q07	.56	Q16	.47
Q08	.47	Q17	.41
Q09	.51	Q18	.51

Table 2: Factor Analysis.

Principal components analysis (unrotated).

(Factor loadings >0.30 shown.)

	Factor 1	Factor 2	Communality Multiple r^2
Next visit	.60		.39
Peak flow meter	.57		.35
See specialist	.68		.45
Action if worse	.60		.31
See Doctor		.58	.21
More reliever		.82	.53
More ICS		.77	.58
Take prednisolone		.69	.44
Check BP	.62		.46
Visitors	.56		.34
Discharge	.69		.48
Nebulisers	.69		.53
Decisions	.71		.51
Dr. if disagree	.70		.50
Hospital decide	.74		.50
Everyday decide		.61	.45
Dr. more control	.64		.37
Check-up need		.62	.44
Eigenvalue	6.8	2.8	
Expl. Variance	47%	17%	

Table 3: Baseline Autonomy Preference Scores:-

Whole sample (N = 286); TQEH subjects (N = 153); LMHS subjects (N = 133).

(Maximum Score 5 = Lowest autonomy - Doctor alone should make decisions).
(Minimum score 1 = High autonomy - Patient alone should make decisions).

Variable	All subjects (Mean ± sd)	TQEH (Mean ± sd)	LMHS (Mean ± sd)	p*
Stable	3.29 ± .82	3.46 ± .88	3.13 ± .73	.001
Mild	2.95 ± .90	2.96 ± .99	2.93 ± .83	.81
Severe	3.67 ± .89	3.76 ± .84	3.59 ± .94	.14
Scenarios	3.20 ± .69	3.40 ± .72	3.21 ± .64	.03
General	3.22 ± .66	3.37 ± .63	3.10 ± .68	.001
Autonomy	3.27 ± .60	3.38 ± .61	3.18 ± .58	.01
'Act. plan'**	2.71 ± .76	2.74 ± .80	2.67 ± .68	.35

** 'Act. plan' = Q5-Q8, Q16, Q18. See Factor analysis text for details.
*p-value based on value of F for comparison TQEH vs LMHS

Table 4: Descriptive Statistics – Q1-Q18.

	TQEH	LMHS	p		LMHS	LMHS	p
Q01	3.37	2.89	.0005	**Q10**	3.16	3.02	.28
Q02	3.21	2.86	.003	**Q11**	3.81	3.63	.06
Q03	3.62	3.39	.025	**Q12**	3.97	3.54	.0008
Q04	3.54	3.24	.008	**Q13**	3.82	3.92	.84
Q05	2.05	1.95	.40	**Q14**	3.30	3.43	.06
Q06	2.97	2.88	.49	**Q15**	3.39	3.40	.96
Q07	3.36	3.38	.87	**Q16**	2.13	1.90	.02
Q08	3.36	3.72	.003	**Q17**	4.27	4.35	.84
Q09	4.25	4.18	.46	**Q18**	2.54	2.17	.003

(** p-values significant at $p < 0.05$ level)

Table 5: Autonomy Preference Index.

Box and Whisker Plot – All patients.

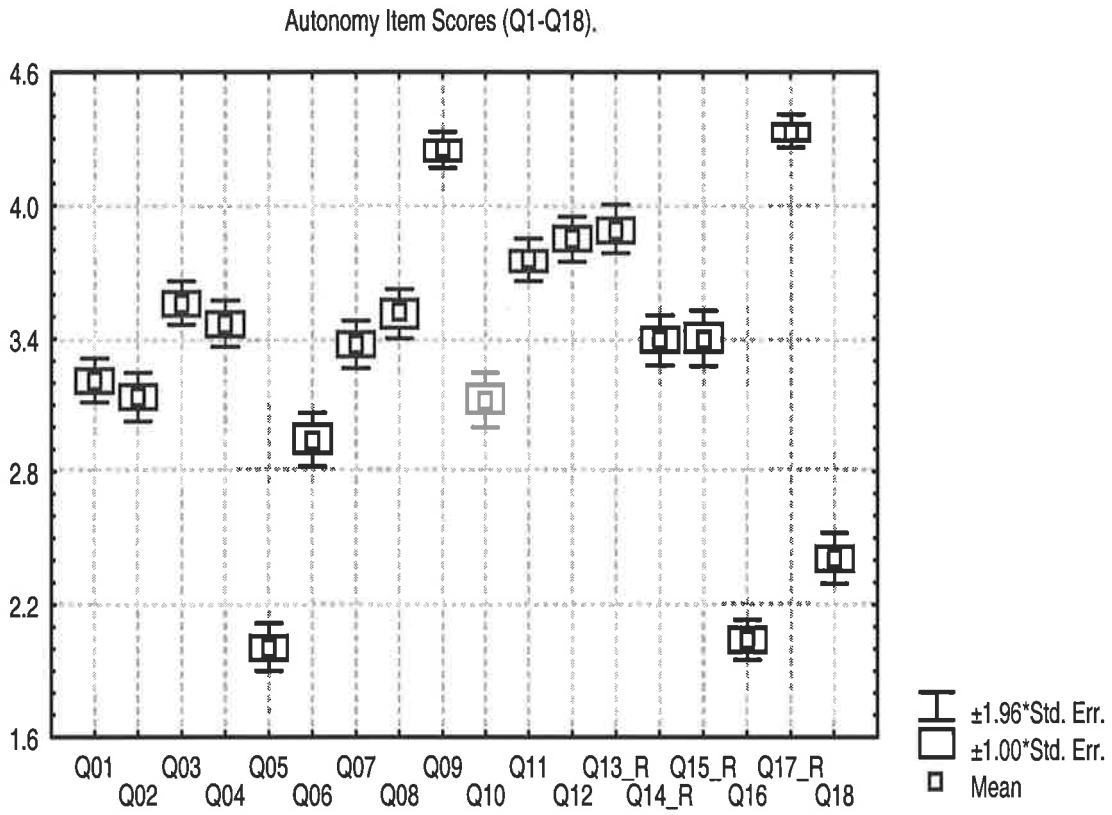

Table 6: Correlations (Pearson r)

All correlations are significant at $p < .00001$

N=252 (Casewise deletion of missing data)

	Stable	Mild	Severe	Scenario	General	Total Aut
Stable		.44	.59	.84	.48	.81
Mild	.44		.30	.76	.32	.69
Severe	.59	.30		.77	.50	.76
Scenarios	.84	.76	.77		.54	.95
General	.48	.32	.50	.54		.78
Total Aut.	.81	.69	.76	.95	.78	
'Act. plan'	.42	.83	.32	.69	.29	.71

Table 7: Autonomy Preference Scores:- Change over 12 months

	TQEH Mean Δ	p*	LMHS Mean Δ	p *
Stable	+0.10	.37	+0.07	.53
Mild	+0.19	.10	+0.16	.16
Severe	+0.15	.14	+0.05	.41
General	-0.05	.45	+0.03	.84
Autonomy	+0.08	.26	+0.08	.28

*: p-value, Baseline vs Score at 12 months

Table 8: Correlations with Psychological and attitudinal variables.

(Values shown only if significant at p< .05 level)

	Confidence	Satis. illness*	Socially desirable+	With-drawal	Active coping	SE concerns	Doctor style**
Stable	.24	.22			.26	.28	.20
Mild	.31	.19		.22	.27	.17	.28
Severe	.19					.26	
Scenario	.32	.25		.20	.29	.30	.22
General			.22			.30	
Total Auto	.29	.24	.17	.20	.26	.34	.26

(* Positive evaluations of asthma/satisfaction with illness)

(+ Tendency to express socially desirable responses)

(** Physician participatory decision-making style)

Correlations with Socio-demographic variables.

	Age	Post-code	Gender	Work-house*	Education level	Costs delay+	Financial difficulty**
Stable	.26				.26		
Mild						.30	
Severe	.19	.26	.18		.22		
Scenario	.17	.17			.25	.26	
General	.33			.19	.37		.23
Total Aut.	.25				.32	.20	.19

(* Anyone working within the household)

(+ Concerns about costs delay seeking needed care for asthma)

(** Financial difficulties within the past 12 months)

Table 9: Prediction of Total Autonomy by linear regression.

Regression Summary

$R = .62$ $R^2 = .38$

$F = 14.6$ $p < .00000$ Std error of estimate: .50

	Beta	SE Beta	B	SE B	t	p
Intercept			3.9	.39	10	
SE concern	.33	.08	.19	.05	4.2	.00006
Education	.27	.08	.12	.04	3.5	.0006
Dr. style	.22	.08	.11	.04	2.85	.004
Confidence	.18	.08	.10	.05	2.15	.024
Active	.17	.08	.06	.04	2.04	.042

Prediction of Autonomy in a Mild exacerbation by linear regression.

Regression Summary

$R = .57$ $R^2 = .32$

$F = 7.6$ $p < .00005$ Std. error of the estimate: .71

	Beta	SE Beta	B	SE B	t	p
Intercept			4.2	.52	8.2	
Confidence	.21	.09	.31	.13	2.6	.017
SE concern	.19	.08	.17	.07	2.3	.023
Dr. style	.18	.08	.16	.06	2.0	.035
Active	.21	.09	.14	.06	2.3	.024
Age	.14	.09	.01	.004	1.6	.10

Table 10: Prediction of Autonomy by Logistic Regression.

Dichotomous outcome of Doctor vs. Patient should make decisions.

Regression Summary:- Likelihood Ratio Statistic: 36.66 on 7 df.

Variables*	Beta	SE (Beta)	95% CI	Odds Ratio	95% CI	p
SE concern	0.65	0.21	0.22; 1.05	1.92	1.3; 2.8	.0025
Education	0.45	0.14	0.13; 0.76	1.45	1.1; 2.0	.015
Dr. Style	0.28	0.13	0.02; 0.55	1.31	1.2; 1.8	.038
Confidence	0.89	0.35	0.21, 1.57	2.43	1.2, 4.8	.01
Active	0.26	0.14	-0.02, 0.5	1.29	0.98, 1.7	.068
Soc. Support	0.77	0.43	-0.06, 1.6	2.16	0.94, 4.97	.07

Odds ratios adjusted for age, sex, and household employment status.

Variables*	Odds ratio	95% CI	p
SE concern	1.74	1.15, 2.63	.006
Education	1.3	0.96, 1.76	.09
Dr. Style	1.40	1.1, 1.95	.032
Confidence	2.39	1.18, 4.82	.014
Active	1.36	1.10, 1.95	.039
Soc. Support	2.3	0.99, 5.3	.053

***Variables:**

Education- > 3 years secondary education

Dr. Style- Score of 7 or less (ie Higher score)

Social support- Score of 7 or more (ie More social support)

Confidence- Reasonably sure can manage asthma

SE Concerns- Concerns about side effects frequently or most of the time prevent from taking asthma medication

Table 11: Prediction of Autonomy in a Mild Attack- Logistic Regression

Dichotomous outcome Doctor vs. Patient should make decisions.

(Adjusted for age, gender, education, and household employment status.)

Regression Summary

Likelihood Ratio Statistic: 21.3 on 5 df.

	Beta	SE (Beta)	95% CI	Odds Ratio	95% CI	p
Confidence	1.04	0.4	0.24, 1.84	2.83	1.3, 6.3	.01
Costs Delay**	-2.2	1.1	-4.4, -0.04	0.11	0.01, 0.96	0.04
Dr. Style	0.28	0.13	0.02; 0.55	1.31	1.2; 1.8	.028
Active	0.26	0.11	0.02, 0.50	1.28	1.1, 1.7	.032
SE concerns	0.25	0.15	-0.03, 0.5	1.3	0.97, 1.73	.082.

(** Concerns about costs delay seeking needed care for asthma)

Table 12: Summary of Physician Participatory Decision Making Style & Patient Satisfaction with Interpersonal Care

(PDM Score range 3 - 15 for Scale. Each Question score range 1 - 5.)

(High score implies Less participatory style)

	Mean Score	95% CI	Reliability (Cronbach A)	Ave. Inter-item correlation
PDM Style (Q13-15)	7.24	6.26, 8.22	0.80	0.58
Choice (Q13)	2.32	2.02, 2.63		
Control (Q14)	2.44	2.04, 2.85		
Responsibility (Q15)	2.54	2.05, 3.03		
Satisfaction with Care*	3.6	3.4, 3.8	0.91	0.52

*High score implies greater satisfaction with care. Score range 1-5

Variations in Participatory Decision-Making Style by Duration of Office visits and Tenure of Dr-Patient relationship.

	Mean PDM Score	95% CI
Length of Office Visits (minutes)		
<5	8.5	6.1, 10.6
6-10	7.6	5.5, 9.7
11-20	7.3	5.8, 8.8
21-30	5.4*	3.9, 6.9
>30	5.0	3.4, 6.3
Tenure Dr-Patient relationship		
First visit	8.5	5.4, 10.8
<6 months	9.0	6.0, 11.1
6 - 12 months	7.2**	3.9, 10.5
1 - 5 years	6.6	5.0, 8.3
> 5 years	6.5	3.8, 9.2

*p<.01 for comparison 11-20 versus 21-30 minutes

**p<.01 for comparison <6 months versus 6-12 months

Table 13: Variations in Participatory Decision-Making Style by Selected Patient Characteristics: Age, Gender, and Education level.

Patient Characteristics	Mean Style Score	95% CI	Mean difference (*p<.05)
Age (years)			
<40	8.8	6.6, 10.9	
41-50	6.25	4.3, 8.4	<40 Vs 41-50 yrs- 2.55*
51-60	7.4	5.2, 9.5	
61-70	7.1	4.9, 9.0	
>70	7.3	5.0, 9.8	
Education level			
<3 yrs Secondary	8.7	6.4, 10.9	Primary Vs 4+ secondary-1.0*
4+ yrs Secondary	7.7	5.4, 10.9	
Tertiary/Further	7.6	5.6, 9.6	
Gender			
Male	7.8	5.7, 10	
Female	7.1	5.9, 8.3	

Variations in Participatory Decision Making Style by Patient's perceived General Health Status

Patient Characteristics	Mean Style Score	95% CI	Mean Difference (*p< .01)
Perceived Health			
Excellent	3.6	3.0, 6.1	Excellent Vs Very Good- 2.1*
Very Good	5.7	2.3, 8.1	
Good	6.1	2.1, 8.2	
Fair	6.3	3.4, 7.2	Fair Vs Poor- 3.3*
Poor	9.6	6.2, 13	

Table 14: Prediction of PDM style by Logistic Regression

Regression Summary for the dichotomous variable of Dr. More vs Less likely to involve patient in management. (Adjusted for age and health status)

Likelihood Statistic: 20.8 on 5 df

	Beta	SE (Beta)	95% CI	Odds Ratio	95% CI	p
Visit length	2.2	0.65	0.8; 3.7	4.2	1.3; 13.8	.018
Tenure Dr.-Pat. relationship	1.1	0.41	0.25; 1.8	2.7	1.3; 5.6	.008

Hosmer-Lemeshow statistic: 7.5 on 8 df p = 0.49

Variables:-

Visit length- > 20 minutes

Tenure Dr-pat. Relationship- > 6 months

Chapter 9

Risk factors for hospital admissions, readmissions, and recurrent presentations to hospital emergency departments.

Introduction

Asthma attacks remain a frequent cause of presentations to emergency departments and of hospitalisations. (1) Although the frequency of these events appears to have reached a plateau in recent years (1), the reduction of acute use of health services for asthma remains a target of health policy. (2)

Numerous studies have indicated a close association between socioeconomic status, residence in economically depressed areas, and asthma morbidity and mortality. (3) In the US, geographic analyses have revealed particularly high asthma hospitalisation and death rates in areas characterised by high rates of poverty and higher proportions of minority group residents. (3-5) Similar findings elsewhere have suggested that socio-demographic factors and the organisation of medical care significantly impact on morbidity, rates of hospital admission and emergency attendance. (6-13) A more recent study from New Zealand showed that patients admitted to hospital with asthma have severe socio-economic disadvantage rather than lower quality of medical care. (8).

Others have indicated that excessive use of beta-agonist medication, inadequate anti-inflammatory treatment, episodic or discontinuity of medical care, coupled with medical non-adherence, psychosocial dysfunction including anxiety, and age are important factors in recurrent emergency department visits, excess hospitalisation and asthma death. (5-8,14-21) A recent study of risk factors for repeat emergency department visits in adults from Adelaide found that predictive factors related to asthma severity as perceived by the patient, and unemployment, were important. (22)

Work from New Zealand has shown that socio-demographic factors can have a major influence on who is offered peak flow meters and self-management programs, even within systems of universal health-care, suggesting physician attitudes play some part in these interactions. (23) Several studies have shown benefits from identifying patients at risk for hospitalisation and emergency service visits, and targeting these groups with more intensive treatment and management. (24,25) It would be useful to identify subgroups of patients on the basis of their health service usage, given the different prognoses of these groups. (26) Very few studies, particularly in the Australian context, have examined clinical status, demographic variables and a broad range of psychosocial factors in relation to health service use. Although not a random community sample, the large range of variables studied in the WRAPP subjects could provide an interesting insight into the factors related to initial health service use and also recurrent use of emergency departments and for re-hospitalisation for asthma.

It was hypothesised that clinical measures of asthma status would be the predominant factors associated with asthma hospitalisation, and that socio-economic status, particularly education and income would be independently associated with admission to hospital. It was hypothesised that for emergency department visits, being driven more by each individual's decision-making, there would be a greater role for psychosocial factors such as coping styles in influencing rates of acute emergency visits.

Methods

Self-reported acute health-care utilisation was obtained as described in Chapter 3, supplemented by case-note review for those lost to survey follow-up.

Separate analyses were conducted for the dependent variables of, (1) at least one hospitalisation, (2) re-hospitalisation (2 or more admissions to hospital), and (3) repeat attendance at an emergency department (2 or more presentations), due to asthma over the 12-month follow-up period. The independent variables measured at baseline and available for analysis are

described in Chapter 3, 'Methods'. Dummy variables were created from the continuous variables. Of particular note for this analysis are: education level was divided into 2 categories based on less than or more than 3 years of secondary education. The BREATHLESSNESS sub-scale of the AQLQ-M was categorised by scores of less than 3, between 3 and 5, and more than 5, (out of a possible 7). Asthma attacks were categorised by the frequency of occurrence, ie more than weekly, more than 3 times/year, less than 3 times/year. Medication dislikes and avoidance coping were categorised by scores of less and more than 4, (out of a possible 7). Physician participatory style (PDM) was included in univariate level analysis although it was only measured at 12 months, as an indicative variable of association of some interest, not as potentially predictive of future events. It was therefore not included in the multivariate analysis.

For the purpose of analysis, control groups for the respective comparisons were patients who indicated they had, (1) not been admitted to hospital, (2) had been admitted once or less, and (3) had attended an ED once or less. Estimated odds ratios for variables adjusted for age, gender, educational level, and household employment status were calculated by multiple logistic regression. (14) In this part of the analysis there was a separate equation for each risk factor of interest. The variables shown were significant at the $p < 0.10$ level. The 5-item socially desirable response scale score was also included as a control variable to assess if this had any impact on the odds ratios. On none of the results was any alteration of odds ratios seen by controlling for this variable. Those with significance at or below $p = 0.10$ were considered as candidate variables for multivariate logistic regression analysis. The objective was to identify the best set of variables that were independently related to the dependent variables. The final model was then assessed for multicollinearity. Adequacy of the fit was assessed by estimation of the deviance, and the Hosmer-Lemeshow statistic. To investigate the effect of simultaneously controlling for socio-demographic differences between cases and controls, odds ratios for the multivariate analysis were also calculated adjusting for age, gender, education level and lack of employment among adults of working age in the household.

Results

Admission to Hospital.

The initial study sample consisted of 293 persons, with 212 completing 12-month surveys. Hospital records from the TQEH and LMHS were examined for those not completing 12-month surveys to ascertain if any asthma-related events (hospitalisations or ED visits) had occurred. It is not known how many of these subjects were truly lost to follow-up (e.g. moved interstate, died) for purposes of this study. Of the study subjects (n=293), 60.6% had no admissions to hospital over the 12 months, 23% were admitted once, and 16.4% had 2 or more hospital admissions for asthma. Therefore, of those admitted to hospital, 41.6% had repeat admissions over the 12 months follow-up period. Of the total sample population, 10.3% had 3 or more admissions to hospital (Table 1).

At the univariate level there were a number of baseline variables associated with at least one admission to hospital over 12 months. Table 2 summarises the odds ratios for variables associated at the level of $p < 0.10$. These principally involved markers of asthma severity such as previous admissions to hospital, self-rated severity, days lost from usual activities and a need for oral steroid medication. Of some interest was that baseline lung function, inhaled steroid dose being taken, and frequency of bronchodilator use were not significantly related to admissions. High baseline quality of life scores significantly reduced the odds of an admission to hospital.

The final model for the multivariate logistic regression analysis showed that a model containing 6 variables provided an optimum fit to the data. (Table 3) Those hospitalised were more likely to have less than 3 years of secondary education; to have been previously to hospital for asthma in the past 5 years; to report having asthma attacks at a frequency of weekly or more often; to use avoidance coping strategies to cope with their asthma; to report more impairment on the BREATHLESSNESS sub-scale of the MAQLQ-M; and to

report not being in possession of a written asthma action plan. Table 4 shows odds ratios adjusted for age, gender, and employment status.

Re-admission to hospital.

Table 5 summarises the odds ratios for those variables associated with re-hospitalisation over the 12 months at the $p < 0.10$ level. Symptoms and reliever medication usage were associated with re-admissions, in addition to the factors related to a single admission. Additional psychosocial variables associated with re-admission were avoidance coping, social support, and the degree of confidence in managing asthma.

The final model for the logistic regression analysis showed that a model containing 6 variables provided an optimum fit to the data (Table 6). Compared with those not admitted or admitted only once, patients admitted on 2 or more occasions were more likely to have been admitted to hospital for asthma over the previous 5 years; to have asthma attacks weekly or more often; to use avoidance coping strategies; to be male; and likely to have more impairment in the BREATHLESSNESS domain of the University of Sydney Quality of Life Questionnaire; or express less acceptance (greater dislike) of taking asthma medications. Adjusting for age, education level and household employment status substantially increased the odds ratios for males and made medication attitudes significant at conventional levels of significance (Table 7).

Repeat attendance at Emergency Departments

Forty-two percent of respondents did not visit the emergency department for their asthma, 25.6% attended on a single occasion, and 32.1% attended on 2 or more occasions (Table 1). This meant that of those patients who attended an ED, 47.3% were repeat (2 or more visits) attenders at EDs. Nearly 18% of the overall sample had 3 or more visits to emergency departments.

Table 8 summarises the odds ratios for those variables associated with re-hospitalisation over the 12 months at the $p < 0.10$ level. Numerous clinical and psychosocial variables were associated with repeat attendances at EDs. Of note was that less frequent GP visits were associated with reduced odds of recurrent emergency visits. Those with lower incomes (<$20,000 pa), and worries about costs of therapy, attended emergency departments more often than those with greater economic resources.

The final model for the multivariate logistic regression analysis showed that a model containing 6 variables provided an optimum fit to the data (Table 9). Compared to subjects who did not attend casualty for asthma or attended only once, repeat attenders were more likely to have been admitted to hospital in the previous year; to be taking regular oral corticosteroids; to be taking asthma medications other than oral or inhaled corticosteroids, or short and long-acting beta agonists (i.e. 'third-line agents'); to have indicated that costs had caused them to delay seeking care necessary for their asthma; to be female; and for no adults of working age in the household to be employed. Adjusting for age and education level brought about some reduction in the odds ratios for the economic variables but these remained significant parts of the model (Table 10).

Discussion

The data shows that acute use of services was common amongst this group of hospital clinic patients. This in part reflects the recruitment of patients from acute events such as ED visits, and from outpatient clinics. Although these events were not counted in the study (which reported events over the succeeding 12 months), it could be expected that these individuals' would be at risk for future morbidity. Recurrent use of services was also common with over 41% having repeat admissions and 47% being repeat attenders at emergency departments. This is similar to that reported by previous authors. Wakefield et al found that 40% of adults with asthma were repeat attenders at EDs, and in the paper from Dales et al in Canada, 56% had recurrent presentations. (14,22)

Several factors emerged as risk indicators for admissions to hospital. One group of variables related to markers of asthma severity- previous admissions, more frequent asthma attacks, and a lower score on the BREATHLESSNESS sub scale of the Asthma Quality of Life Questionnaire. A number of other indicators of clinical severity were significant in the univariate analyses. Interestingly, dose of inhaled corticosteroids (ICS) was not a significant factor associated with hospital admissions or recurrent emergency visits. This may be due to many influences on the amount of this medication actually used by patients. These include the prescription by the physician, which is affected by prescribing habit and temperament, and in turn can be affected by the measured clinical features of the patient but also by the manner and personality of the patient. (17) The patients' adherence to the regimen is the result of a complex analysis of the difficulty of fitting the medication regime into their life. (27) The reporting of medication use is likewise a process depending on many competing factors and is frequently inaccurate, resulting in both under- and over-reporting of medication use. (27,28) This is likely to have occurred here, despite the low demand characteristics of the postal survey, the separation of the research workers and the clinical staff caring for patients, and the specific, non-judgemental nature of the questions posed. Respondents were asked to give the actual dose of ICS they were taking currently not that prescribed, hence all of the above factors may have come into play to reduce the association of recorded ICS dose and health service use outcomes. If nothing else, the results show the methodological difficulties present with this type of research. Without some form of objective measurement of inhaler use it will be difficult to accurately know what patients are taking, and the consequences of this usage or non-usage. This contrasts with the findings for oral steroids and 'other' asthma medications, which were classified as using these medicines or not and hence avoid the issues of how much and how often they were being taken.

The study patients had a number of indicators of good ongoing care- over 80% of the study patients indicated taking some dose of inhaled

corticosteroids, and 55% had a written action plan and over 70% stating they had an 'action plan' of what to do in an acute attack. This compares with results from a South Australian community sample of asthmatics, where 42% recalled being provided with an action plan of some type, and 52% were using inhaled corticosteroids. (1) Of those not taking any ICS medication at baseline, 40% were admitted to hospital and 45% had recurrent presentations to Emergency Department. Whether this relates to under-prescription of medication, patient non-adherence, or inaccurate reporting cannot be ascertained from the data available.

Dales et al identified moderate to severe asthma chronically under poor control as a potentially modifiable risk factor for asthma exacerbations requiring emergency care. (14) Increasing the prescription of inhaled corticosteroids has been shown to reduce asthma exacerbations. (29) It has been shown to reduce hospitalisations in a study using pharmacy records linked to administrative data. (30) Increased ICS dose was also a feature of one of the few trials of an asthma management program that demonstrated a significant reduction in hospitalisation. (24) In the study population, 83% of those experiencing asthma attacks more than weekly were taking inhaled corticosteroids at some dosage, 67% were taking over 1000 mcg/day, and a further 21% were taking oral corticosteroids. The data suggests that some reductions in recurrent health service use may be possible by the use of more intensive treatment regimens in a small group of hospital clinic patients. However, the issues discussed above regarding adherence, plus the identification of avoidance coping and medication dislikes as a significant predictors of hospital admissions and/or re-admissions, would caution against excessive optimism that asthma admissions can be easily reduced by the simple expedient of increasing the prescribed inhaled corticosteroid dosage. The complex interaction between patient attitudes, temperament, socio-economic status and physiological severity, requires also changing the physicians' approach by explaining the risk benefits of medication, and developing new approaches to reducing morbidity.

Using avoidance coping strategies was a significant predictor of admissions and recurrent admissions to hospital. This emotion-focused style of dealing with the problems of asthma was also shown to be a strong predictor of quality of life (see Chapter 5). This is an approach to problems that consists of refusing to take any steps to actively deal with them, and also withdrawing from contact with others and becoming isolated, physically and psychologically. That this is associated with reduced quality of life in both physical and mental health domains, and with increased asthma morbidity is not surprising. It presents clinicians with a difficult challenge to address this problem in order to improve patients' asthma outcomes. Lazarus has suggested that coping styles are neither 'good' nor 'bad' but are contingent on the circumstances of the situation. However, he has indicated that the evidence would suggest that avoidance-type coping styles appear to be counter-productive and bring about worse health outcomes. (31,32) Avoidance coping may operate negatively at several levels in affecting asthma patients. Individuals may avoid the regular use of preventive medications leading to poorer control of asthma symptoms and increasing risk of hospitalisation. In an acute exacerbation this response style may cause the patient to delay initiating appropriate changes to treatment or in seeking medical help. Withdrawing from social contact may reduce the buffering effect of social support which can then increase the risks of poorer outcomes. (33)

That adherence to medications is generally low in asthma is well established. (27,34,35) That some patients refuse to accept the use of regular medications or deny the chronic nature of their asthma has also been reported as a significant factor in non-adherence to treatment regimens. (36-38) This data indicates that emotion-focused, avoidance coping and a dislike of the regular use of asthma medications predicts worse outcomes, ie hospital admissions. This has been described as a form of 'magical thinking', leading people to hope that "if they stop taking the medicine the illness will disappear, which it does from to time anyway" in asthma. (39) People do not like to be reminded that they are different from others who do not depend on medicines. (37) Interventions may need to be focused on these specific

issues rather than generically on 'asthma education', in order to achieve less morbidity. How this may be achieved is less clear. Cognitive-behavioural interventions to assist patients' reappraisal of situations may be one approach. (40) The physicians' approach to patient participation and autonomy, as discussed in Chapter 8, may be an important long-term factor in influencing these attitudes. Attention to the factors influencing those variables, such as visit length and the tenure of the patient-provider relationship, may be needed at the level of policy development and not just by individual clinicians. Side-effect concerns, which were related to patient autonomy preferences (see Chapter 8), were also related to the level of acceptance or dislike of regular asthma medication and whether these medications are taken. These factors were in turn associated with re-admissions to hospital for asthma. A resentment of regular medication use, in combination with other factors, such as those described by Adams et al relating to identity and self-concept, and more pragmatic worries about side-effects, exert a major influence on medication usage. (36)

The role of the physician should not be lightly dismissed. The influence of the doctor in addressing medication concerns and fears, suggesting practical ways they can be used in everyday living, and in framing their use in the positive light as a means of achieving asthma control, are critically important. In addition, adherence by clinicians to the published asthma management guidelines may improve outcomes, as indicated by the significant effect on admission rates of not providing a written asthma action plan to patients. Males were less likely to report having a written action plan ($p = .0032$), a factor of importance in recurrent admissions to hospital. Gibson et al have indicated in a systematic review that to improve outcomes, a written action plan seems to be a critical part of self-management programs. (41)

The predictive validity of quality of life instruments has been largely ignored in lung disease. (42) Two recent studies have demonstrated good predictive validity of disease-specific measures in elderly Chronic Obstructive Pulmonary Disease (COPD) patients, but there has been little published work in asthma. (43,44) All domains of the MAQLQ-M were significantly related to

hospital admissions, readmissions and repeat emergency attendances in the univariate analyses. The BREATHLESSNESS sub-scale remained part of the multivariate model. This demonstrates the predictive validity of the MAQLQ-M, i.e. its ability to predict future changes in health-care needs. The results provide further evidence of the usefulness of the MAQLQ-M as a tool in assessing longitudinal health status in both clinical and research settings. Both component summary scales of the SF-36 were also significantly related to the outcomes of health service use assessed here. Although not part of the final multivariate model, this data supports the usefulness of this generic health status instrument as a tool in measuring asthma outcomes. It is also consistent with other published work demonstrating the predictive validity of the SF-36 summaries in other conditions. (45)

Socio-economic factors have been implicated in higher acute health service use for asthma. (5,6,8,11,14,15,15,20-22) Part of this phenomenon has been attributed to less use of ambulatory care, for a variety of reasons. Like Dales et al, in this study population frequent visits to a general practitioner did not reduce the use of the emergency department or hospital admissions. (14) The data do not support the contention that patients using acute services are substituting this for help from their general practitioner, as over 45% of those seen more than 6 times over the 12 months for their asthma had admissions to hospital or repeat attendances at EDs. Rather, they are seeking help from any source available. Seeking care does not necessarily mean high quality care will be provided or that the patient will act on the advice given. To some extent more visits to the GP may simply reflect more severe asthma, as more symptoms predicted more use of health services. A high level of medication prescription was also not necessarily protective- those on oral steroids or third-line medications (eg theophylline, ipratropium bromide) had increased risks of repeat ED presentations.

The other factor leading to excess use of ED services was the problem of costs inhibiting seeking care. This may be mediated via under-or inappropriate medication over prolonged periods, not filling prescriptions, or by delays in attending the general practitioner during attacks. Although not

specifically asked of the patients, delaying filling a prescription due to the cost is a likely problem, and may also in part explain the high rate of primary non-compliance reported previously in asthma patients in South Australia. (46) Kolbe and colleagues have reported that failure to fill a prescription due to cost occurred in 34% of their patients, and that this was significantly associated with asthma morbidity. (8) Although gross income was not related to recurrent presentations in the multi-variate model, unemployment was a significant predictive variable. Employment status, in the literature, is the most consistent social factor predicting patient distress and greater use of emergency services. (47) Less than 3 years of secondary education was predictive of hospital admissions, even when controlled for the effects of age, and employment. This is generally similar to previous studies that have shown associations between increased acute use of health services and unemployment (22,48), low income (11,15,20), lower education (22), or combinations of all these factors (3-5,8,10,49).

Lower education and economic disadvantage may reduce the ability of patients to maximise the benefits of any educational or self-management intervention. Some evidence to support this can be seen from the fact that those with less formal education were significantly more likely to have a written action plan ($p= .0017$), but were nonetheless more likely to be admitted to hospital. Whether this is because providing an action plan is insufficient to overcome more powerful determinants of asthma morbidity, or that educational disadvantage prevents the timely activation of action plans is not known. Education also affects the patients' desire for decision-making self-management autonomy (Chapter 8). Investigating if teaching self-management with specific regard to the educational level of the patient, and stressing the area of autonomous decision-making, will improve outcomes is a potentially fruitful area for future research. The data support the contention that there is a need to address fundamental socio-economic factors before attempting to teach self-management skills because, otherwise we are likely to be largely wasting our time and not knowing it. (8) Further work to more accurately define what aspects of costs limit asthma care is needed. Whether this is purely a matter of the expense of medications, or a more

complex issue relating to spending priorities and valuing health, needs determining. Delays in seeking care due to concerns about missing work were not a feature in this sample, which may in part reflect the high degree of welfare dependence of the sample.

Conversely, to ignore the personal determinants that affect health behaviour may be to miss areas where changes can be made. More generally, the results show that failing to look at the patient in the context of their whole life and considering the socio-economic, psychological and attitudes and beliefs of patients, the current reductions in asthma morbidity and mortality may not continue.

Criticism can be made of the study sample and hence the generalisability of the results. Patients were recruited opportunistically at outpatient clinics, or from emergency visits and hospital admissions. Community persons with asthma were thus excluded, as were non-metropolitan patients. On the other hand, in a study seeking to identify the factors leading to high usage of acute health services, focusing on those at high risk and who have a higher burden of asthma has advantages. There were no significant differences in socio-demographic characteristics between those patients who enrolled in the study and those who did not complete the baseline survey. The sample population was broadly similar in socio-demographic make-up to the population of the North-Western suburbs of Adelaide which is the catchment area of the two hospitals. There was no measure of the severity of any exacerbation leading to admission or casualty presentation; thus it is difficult to know if the increased frequency of acute visits represents a lower threshold for presentation in those patients or their carers. The association of a number of markers of asthma severity with increased hospital use suggests that this is not a major factor. Confirmation of this with some form of external assessment of the severity of an exacerbation could be made in a future study. The inclusion of patients from two hospitals broadens the perspective of the study more than if patients came from a single clinic or hospital. However, the north-western area of Adelaide is relatively economically disadvantaged and the risk of the results being influenced by hospital-specific

factors exists. Conversely, if one accepts the evidence that socio-economic status is associated with worse health outcomes (50-52), then investigating what other specific elements may contribute to poorer health in these groups may turn up some potentially remediable risk factors. It should be noted that males were less likely to have repeated attendances at the ED, but were more likely to be readmitted to hospital. Whether this reflects gender differences in patient perception of the severity of episodes, or different gender attitudes by medical staff, or is a consequence of the gender imbalance of the sample, is unclear.

A possible limitation of the study is the lack of a unitary measure of socio-economic status (SES). (8) All standard measures of SES such as income, employment, income source and education were included. All measures were based on self-report and may be subject to a tendency for some respondents to give socially desirable responses. Using the 5-item response set of socially desirable response set (see Chapter 3, 'Methods'), as a control variable resulted in no change to the results. Kolbe et al have reported that people tend to under-report their level of economic disadvantage. (8) The addition of specific questions covering the financial implications of asthma care measures the impact of the direct costs of asthma care on individuals, and may be a more useful guide to the relation between economic problems and asthma outcomes.

To summarise, use of acute health services is related to markers of asthma severity and socio-economic factors such as education level and financial limitations. There is also a significant relationship to personal psychological and attitudinal variables, such as avoidance coping and a dislike of taking regular asthma medication. With regard to the study hypotheses, contrary to expectations, psychosocial factors, such as education and avoidance coping, were found to be as important as clinical status in predicting future hospital admissions. For repeat emergency visits, socio-economic disadvantage rather than other psychological parameters were major associations with future events. Quality of care, as measured by the provision of written asthma action plans, was also related to health-care needs. While

awareness of the major influence of SES factors on health needs to be maintained, it is to these other, potentially remediable, elements of poorer asthma outcomes that ongoing attention must also be directed to continue the improvements made in recent years.

Table 1: Proportion of patients Admitted to hospital for Asthma over 12-months assessed by socio-demographic variables.

	No. of Visits		
Variables (%)	**0**	**1**	**2+**
Whole Sample	60.6	23	16.4
Males	60	18.2	21.8
Females	59.3	24.8	15.9
Unemployed	42.7	24	33.3
Employed	58.9	20	21.1
Education -			
<3 years Secondary	40	40	20
>3 years Secondary	52.5	34.4	13.1

Proportion of patients with Emergency Department Attendances for Asthma over 12-months assessed by socio-demographic variables.

	No. of Visits		
Variables (%)	**0**	**1**	**2+**
All Sample	42.3	25.6	32.1
Males	50.9	20	29.1
Females	38.7	28.8	32.5
Unemployed	42.7	24	33.3
Employed	43.3	27.8	28.9
Education -			
<3 years Secondary	25.5	32.7	41.8
>3 years Secondary	44.4	26.7	28.9

Table 2: Odds ratios for variables associated with Hospital admission.

Indicators of asthma control, care quality, co-morbidity, by hospital admissions

Baseline Variables	Adjusted OR++	95% CI	p - value
Hospital admission past 5 years	1.6	1.3, 1.99	.0000
Taking Oral steroids	2.65	.99, 7.05	.051
Taking Other asthma medication*	1.96	.93, 4.15	.079
Self-rating of Asthma (severity) over the past 3 months – None or Mild	0.74	.51, 1.06	.10
Feels asthma generally getting worse	2.18	1.24, 3.83	.0066
Lost some days from usual activities in the last 3 months due to asthma	1.18	0.99, 1.41	.069
GP visits for asthma in past year: 0-3	.30	.13, .67	.0035
No Written Asthma Action Plan	3.41	1.51, 7.71	.0033
Physician's participatory style – low	1.96	1.20, 3.21	.0095
Other Significant Medical Conditions**	2.06	.97, 4.39	.06

*Medication other than oral or inhaled corticosteroids; or short or long acting beta agonists.

**Cardiac, cerebrovascular, or renal disease, hypertension, diabetes, or disabling arthritis.

Asthma quality of life, and patient attitudes by hospital admission.

Baseline Variables	Adjusted OR++	95% CI	p - value
BREATHLESSNESS*	.66	.50, .86	.002
MOOD*	.61	.45, .82	.0012
CONCERNS*	.64	.50, .83	.0008
SOCIAL*	.66	.51, .83	.0006
TOTAL/OVERALL*	.58	.43, .78	.0003
PCS (SF-36)**	.66	.42, .90	.0018
MCS (SF-36)**	.65	.40, .88	.0016
Medication dislikes- least dislike	.79	.64, .97	.027

*Upper 25% of each sub-scale on the MAQLQ-M.

**Upper 25% of SF-36 Physical / Mental Component Summary scores

++Odds ratios were adjusted for age, gender, education, and household employment.

Table 3 : Prediction of admission to hospital by multiple logistic regression.

Regression Summary

Variables**	Beta	SE (beta)	95% CI	Odds Ratio	95% CI	p
Education	0.47	0.12	0.24, 0.71	1.6	1.27, 2.03	.0001
Admission past 5 years	0.36	0.11	0.14, 0.59	1.4	1.15, 1.80	.0015
Attacks	0.36	0.18	0.01, 0.71	1.4	1.01, 2.03	.042
Avoidance	0.64	0.23	0.18, 1.1	1.53	1.34, 1.83	.0059
Breathless	-0.35	020	-0.74, 0.04	0.7	0.47, 1.02	.076
No Written plan	0.60	1.12	-1.59, 2.78	2.4	0.86, 6.74	.094

Deviance	130 on 138 df;
Likelihood statistic	76 on 7 df.
Hosmer-Lemeshow statistic	6.3 on 8 df p = 0.61

****Variables:-**

Admission 5 years= Any hospital admission for asthma in the past 5 years

Attacks = Frequency of asthma attacks (> = weekly)

Breathless = Higher score on the BREATHLESSNESS domain of the MAQLQ-M

Avoidance = Avoidance coping style

Written plan = Reported possession of a written asthma action plan

Education = Less than 3 years secondary education

Table 4: Prediction of admission to hospital by multiple logistic regression: Adjusted odds ratios.

Odds ratios adjusted for age, gender, and household employment status

Variables**	Odds ratios	95% CI	p
Education	1.61	1.26, 2.05	.0001
Admission past 5 years	1.44	1.13, 1.83	.003
Attacks	1.42	1.0, 2.01	.05
Avoidance	1.53	1.35, 1.86	.0096
Breathless	0.74	0.46, 1.14	.17
No Written plan	2.23	0.75, 6.64	.148

Odds ratios adjusted for age and gender.

Variables**	Odds ratios	95% CI	p
Education	1.61	1.26, 2.05	.0001
Admission past 5 years	1.42	1.13, 1.79	.003
Attacks	1.44	1.02, 2.04	.04
Avoidance	1.53	1.33, 1.85	.0092
Breathless	0.71	0.47, 1.06	.091
No Written plan	2.36	0.80, 6.89	0.11

****Variables:-**

Admission 5 years= Any hospital admission for asthma in the past 5 years

Attacks = Frequency of asthma attacks (> = weekly)

Breathless = BREATHLESSNESS domain of the MAQLQ-M

Avoidance = Avoidance coping style

Written plan = Reported possession of a written asthma action plan

Education = Less than 3 years secondary education

Table 5: Odds ratios for variables related to Hospital Re-admission.

Indicators of asthma control, care quality, co-morbidity, by Re-admissions

Baseline Variables	Adjusted OR++	95% CI	p – value
Hospital admission past 5 years	1.86	1.47, 2.36	.0000
Taking Oral steroids	3.13	1.14, 8.6	.027
Taking Other asthma medication*	3.42	1.32, 8.8	.011
Taking Long-Acting Beta agonists	8.3	2.9, 23.7	.0001
Reliever medication use < 1x/weekly	.18	.03, .91	.039
Morning Symptoms- < 3 monthly	.74	.53, 1.04	.083
Exercise impairment- none or sport	.76	.59, .98	.035
Symptom Total- least severity	.87	.77, .97	.013
Self-rating of Asthma (severity) over the past 3 months – None or Mild	.54	.33, .87	.011
Feels asthma generally getting worse	2.90	1.40, 6.03	.0043
Lost some days from usual activities in the last 3 months due to asthma	1.07	1.01, 1.13	.019
No Work impairment by asthma	.73	.58, .92	.0085
GP visits for asthma past year- 0-3	.20	.06, .66	.0077
No Written Asthma Action Plan	3.12	1.48, 7.13	.0039
Physician's participatory style – low	2.46	1.18, 4.15	.0078
Other Significant Medical Conditions**	2.53	1.03, 6.2	.044

*Medication other than oral or inhaled corticosteroids; or short or long acting beta agonists.

**Cardiac, cerebrovascular, or renal disease, hypertension, diabetes, or disabling arthritis.

++Odds ratios were adjusted for age, gender, education, and household employment.

Table 5: Odds ratios for variables related to Hospital Re-admission. (continued)

Asthma quality of life, and patient attitudes by hospital re-admission

Baseline Variables	Adjusted OR++	95% CI	p – value
BREATHLESSNESS*	.41	.27, .61	.0000
MOOD*	.50	.34, .73	.0004
CONCERNS*	.53	.38, .74	.0001
SOCIAL*	.57	.42, .76	.0002
TOTAL/OVERALL*	.43	.29, .64	.0000
PCS (SF-36)**	.50	.32, .75	.0006
MCS (SF-36)**	.55	.40, .72	.0001
Medication dislikes- least dislike	.64	.53, .92	.0101
More Confidence/Self-efficacy	2.42	1.11, 5.27	.026
Low Avoidance Coping Style	.52	.36, .75	.0005
Low level perceived Social Support	1.44	1.06, 1.96	.0227

*Least impairment for each sub-scale on the MAQLQ-M.

**Upper 25% of SF-36 Physical / Mental Component Summary scores

++Odds ratios were adjusted for age, gender, education, and household employment.

Table 6: Prediction of Re-admissions to hospital by multiple logistic regression.

(Readmission = 2 or more admissions to hospital over 12 months.)

Regression Summary

Variables**	Beta	SE (beta)	95% CI	Odds Ratio	95% CI	p
Admission past 5 years	0.64	0.15	0.35, 0.92	1.9	1.42, 2.51	.0000
Breathless	-1.1	0.32	-1.7, -0.47	0.3	0.18, 0.63	.0006
Attacks	0.65	0.28	0.10, 1.19	1.9	1.11, 3.28	.019
Avoidance	0.78	0.39	0.01, 1.55	2.2	1.01, 4.73	.046
Male Gender	1.60	0.77	0.08, 3.12	5.0	1.08, 22.7	.038
Med. dislikes	-0.50	0.27	-1.02, 0.03	0.6	0.36, 1.03	.063

Deviance	72 on 145 df;
Likelihood statistic	138 on 7 df.
Hosmer-Lemeshow statistic	4.3 on 8 df p = 0.81

****Variables:-**

Admission past 5 years =	Any hospital admission for asthma over 5 years
Attacks =	Frequency of asthma attacks (> = weekly)
Breathless =	Higher score on the BREATHLESSNESS domain of the MAQLQ-M
Avoidance =	Avoidance coping style
Med. Dislikes =	More Acceptance (Less Dislike) of taking asthma medications

Table 7: Prediction of Re-admissions to hospital by multiple logistic regression.

Odds ratios adjusted for age, education level and household employment status.

Variables**	Odds ratios	95% CI	p
Admission past 5 years	2.23	1.53, 3.27	.0000
Breathless	0.28	0.13, 0.61	.0014
Attacks	2.07	1.09, 3.94	.026
Avoidance	2.95	1.20, 7.29	.019
Male Gender	12.2	1.87, 80.0	.009
Med. dislikes	0.56	0.32, 0.99	.049

Odds ratios adjusted for age and education level.

Variables**	Odds ratios	95% CI	p
Admission 5 years	2.24	1.53, 3.28	.0000
Breathless	0.29	0.14, 0.60	.0008
Attacks	2.04	1.09, 3.84	.026
Avoidance	2.95	1.20, 7.29	.019
Male Gender	12.6	1.97, 81.0	.007
Med. dislikes	0.56	0.32, 0.99	.046

****Variables:-**

Admission past 5 years =	Any hospital admission for asthma over 5 years
Attacks =	Frequency of asthma attacks (> = weekly)
Breathless =	BREATHLESSNESS domain of the MAQLQ-M
Avoidance =	Avoidance coping style
Med. Dislikes =	More Acceptance (Less Dislike) of taking asthma medications

Table 8: Odds ratios for variables related to Repeat attendance at Hospital Emergency Departments.

Indicators of asthma control by repeat emergency attendance.

Baseline Variables	Adjusted OR++	95% CI	p
Hospital admission past 5 years	1.42	1.20, 1.68	.0000
Taking Oral steroids	12.1	3.85, 38.1	.0000
Taking Other asthma medication*	5.53	2.31, 13.7	.0001
Taking Long-Acting Beta agonists	6.19	2.27, 16.9	.0004
Reliever medication use < 1x/weekly	.14	.02, 1.27	.08
Morning Symptoms- < 3 monthly	.74	.56, .97	.03
Exercise impairment- none or sport	.80	.64, .99	.044
Symptom Total- least severity	.90	.83, .99	.029
Self-rating of Asthma (severity) over the past 3 months – None or Mild	.47	.31, .72	.0006
Self-rating of Control of Asthma over the past 3 months – Poor	1.26	.96, 1.64	.095
Feels asthma generally getting worse	2.81	1.54, 5.12	.0008
No days lost from usual activities in the last 3 months due to asthma	.26	.12, .58	.0009
No Work impairment by asthma	.70	.57, .86	.0007
GP visits for asthma past 12 months- 0-3	.24	.10, .57	.0014
GP visits for asthma past 12 months- 4-6	.37	.12, 1.1	.076
No Written Asthma Action Plan	3.12	1.48, 7.13	.0039
Other Significant Medical Conditions	2.53	1.03, 6.2	.044

*Medication other than oral or inhaled corticosteroids; or short or long acting beta agonists.

**Cardiac, cerebrovascular, or renal disease, hypertension, diabetes, or disabling arthritis.

++Odds ratios were adjusted for age, gender, education, and household employment.

Table 8: Odds ratios for variables related to Repeat attendance at Hospital Emergency Departments. (continued)

Asthma quality of life, patient attitudes and socio-demographic factors by repeat emergency attendance.

Baseline Variables	Adjusted OR++	95% CI	p – value
BREATHLESSNESS *	.51	.37, .70	.0000
MOOD *	.58	.43, .80	.0006
CONCERNS *	.57	.42, .75	.0001
SOCIAL *	.59	.45, .76	.0001
TOTAL/OVERALL *	.47	.34, .67	.0000
PCS (SF-36)**	.56	.41, .75	.0002
MCS (SF-36)**	.61	.48, .76	.0011
Medication dislikes- least dislike	.72	.58, .90	.0034
High Active coping style	.75	.55, 1.03	.077
Low Avoidance Coping Style	.61	.45, .83	.0015
Low level perceived Social Support	1.76	1.26, 2.44	.0008
Gross Income < $20,000 per annum	6.39	.84, 48.9	.074
Cost concerns delay seeking care	2.56	1.01, 6.53	.048

*Least impairment for each sub-scale on the MAQLQ-M.

**Upper 25% of SF-36 Physical / Mental Component Summary scores

++Odds ratios were adjusted for age, gender, education, and household employment.

Table 9: Prediction of Repeat Attendance at Hospital Emergency Departments.

(Repeat Attendance = 2 or more presentations over 12 months.)

Logistic Regression Summary

Variables**	Beta	SE (beta)	95% CI	Odds Ratio	95% CI	p
Admission past 12 months	1.07	0.25	0.58, 1.56	2.92	1.78, 4.79	.0000
Oral Steroids	2.63	0.76	1.13, 4.12	13.9	3.12, 61.7	.0005
Other asth. med	1.18	0.50	0.19, 2.16	3.24	1.20, 8.72	.019
Costs delay care	1.71	0.62	0.49, 2.92	5.52	1.64, 18.62	.006
Male Gender	-1.16	0.55	-2.24, -0.09	0.31	0.11, 0.92	.035
Unemployment	1.46	0.54	0.40, 2.51	4.3	1.50, 12.3	.0067

Likelihood statistic:	81.6 on 6 df.
Deviance	108 on 136 df
Hosmer-Lemeshow	8.5 on 6 df; p = 0.21

****Variables:-**

Admission past 12 months =	Any hospital admission for asthma in the previous year.
Oral Steroids =	Taking oral prednisolone regularly at baseline.
Other asth. Med. =	Taking asthma medications other than inhaled or oral corticosteroids; and short or long-acting beta-agonists.
Costs delay care =	Concerns about costs have delayed seeking needed care for asthma.

Table 10: Prediction of Repeat Attendance at Hospital Emergency Departments.

Odds ratios adjusted for age and education level.

Variables**	Odds ratios	95% CI	p
Admission past 12 months	2.88	1.71, 4.84	.0001
Oral Steroids	11.2	2.49, 50.2	.0016
Other asthma medications	4.67	1.56, 14.04	.0060
Costs delay care	3.86	1.05, 14.1	.041
Male Gender	0.32	0.10, 0.98	.046
Unemployment	2.67	0.80, 8.45	.10

****Variables:-**

Admission past 12 months = Any hospital admission for asthma in the previous year.

Oral Steroids = Taking oral prednisolone regularly at baseline.

Other asth. Med. = Taking asthma medications other than inhaled or oral corticosteroids; and short or long-acting beta-agonists.

Costs delay care = Concerns about costs have delayed seeking needed care for asthma.

Chapter 10

Conclusions

This thesis has addressed a number of issues concerning the psychosocial aspects of asthma health outcomes. The research project was a longitudinal observational study of subjects with asthma recruited from two hospitals in metropolitan Adelaide, South Australia. Subjects were administered a number of questionnaires at 3-monthly intervals over 12 months. Lung function and health service use was also monitored.

The principal research questions centred around measurement of health-related quality of life (HRQL), the meaning of score changes in HRQL instruments, and the factors that influence HRQL in hospital asthma patients. Other questions addressed concerned the determinants of self-management autonomy preferences and the factors that influence health service usage by patients.

Hypotheses

With regard to the specific hypotheses of each chapter, the results of Chapter 4 did show that the MAQLQ-M had superior construct and longitudinally validity to the SF-36 in this group of patients. The modified version, as anticipated, showed improved reliability and responsiveness values compared to previously published values for the AQLQ-M. The SF-36 was able to discriminate between levels of health according to symptom frequency and work days lost. From Chapter 5, whilst avoidance coping and economic disadvantage was negatively associated with HRQL, the expected independent associations with HRQL of self-efficacy, active coping and social support were not seen. Further, clinical status was not more strongly predictive of changes in HRQL scores than certain psychosocial variables, as was expected to be the case.

From Chapter 6, it can be seen that both stated hypotheses were proven, ie that the MCID of this 7-point scale was similar to that of other scales using 7-

point Likert responses, and that the MAQLQ-M was more sensitive to small changes than the SF-36 component summaries. In Chapter 7, it was hypothesised that IRT models would show that both HRQL instruments, when scored in the usual summative manner, were not linear scales and not equidiscriminating across the spectrum of HRQL. The results were in accord with these hypotheses. In Chapter 8, as predicted, autonomy preferences wer not associated with clinical measures of severity of quality of life, but to psychosocial factors, such as the level of medication side effect concearns, self-efficacy and active coping style. In Chapter 9, the results showed that, contrary to expectations, psychosocial factors, such as education and avoidance coping, were found to be as important as clinical status in predicting future hospital admissions. Conversely, for repeat emergency visits, psychological parameters were found to be of lesser significance than socio-economic disadvantage.

Quality of Life in asthma: measurement.

The Marks AQLQ (AQLQ-M) had previously been shown to be a valid measure of HRQL in asthma (1,2), however some questions remained about its use. Its validity as a measure of deterioration in health status had not been determined, hence its usefulness in a clinic setting could not be assumed. (3) Further, with a reliability coefficient alpha of around 0.90 (1,4,5), the standard error of measurement is almost one-third as large as the standard deviation of test scores. Hence errors in classification can occur if a single test cut-point is used for decision making. In an attempt to reduce this (6,7), the AQLQ-M was modified to use a 7-point Likert response scale (MAQLQ-M). However, it is possible that a test can be made too stable to reliably detect small, but real changes in quality of life. (6,8) The methodological issues addressed in this thesis related to the criterion validity of the modified instrument, and its validity as a measure of both improvement and deterioration in HRQL. The results, in subjects recruited from two hospital settings, indicated that the MAQLQ-M was reliable, and was valid as a discriminative cross-sectional instrument, and as an evaluative measure of small changes within subjects over time. The absence of floor and ceiling effects, despite substantial proportions reporting either no symptoms or

frequent symptoms in many categories, suggests it is a useful tool in discriminating between different levels of health, and remains effective at the extremes of HRQL. It was as sensitive to change when compared with disease reference measures as it was to discriminating between subjects at a single point in time, a feature it shares with the Juniper AQLQ. (9) Other asthma-specific questionnaires usually have excellent cross-sectional validity, but are less sensitive to within-subject changes. (1,2,10-12) The strength of associations with other measures of disease activity was greater for the modified instrument in this population than reported for the original questionnaire. (2) However, direct comparison with the original AQLQ-M as a measure of change requires a comparison trial in a single sample. Future research is needed to compare the MAQLQ-M and the Juniper AQLQ in different populations to assess the relative validity and responsiveness of these instruments. The advantages in more easily allowing comparisons across populations and patients, and the administrative simplicity of the MAQLQ-M and its advantage in allowing comparisons across populations, could potentially make it the instrument of choice in research and clinical settings.

The current study has confirmed the reliability, and the convergent and longitudinal validity, of the SF-36 in an English-speaking sample with a wide range of asthma severity. The absence of floor and ceiling effects demonstrated the advantage of the Physical and Mental Component Summaries over the 8 domain scales of the SF-36. For a number of relations with markers of disease severity, the SF-36 Component Summaries performed in the same range as the MAQLQ-M. The MAQLQ-M did show the stronger relation with symptoms, medication use and lung function. The two surveys showed strong correlations with each other. Significant differences were seen between the population-norms for the SF-36, and the scores of a random community sample of people with asthma, with a hospital-based asthma sample having lower scores again. It was also possible to compare scores for community samples of people with other chronic conditions, such as diabetes. Both HRQL measures demonstrated predictive validity against hospital admissions over 12 months. This study has therefore shown that there is a place for both generic and disease-targeted measures to gain a

clear picture of patient asthma health outcomes. The use of disease-specific or generic instruments will depend on the research question being asked. The greater construct validity of the disease-targeted tool (MAQLQ-M), is to some degree balanced by the comparative ability of the generic instrument (SF-36).

Similar to previous work, the data emphasises that clinical measures are limited in closely predicting the day-to-day functioning of patients. (1,9,12) The implication of this is that quality of life measures add complementary information to conventional clinical outcomes. The level of psychosocial distress or 'bother' from asthma will be underestimated if clinical measures of symptoms and lung function are the only means of assessment used. This may be particularly so in a hospital-based population where mental and physical health are probably more closely interlinked than would be the case for a healthy population. (13) Thus, the similarity of scores for the two components of the SF-36 and for all the sub-scales of the MAQLQ-M may reflect the characteristics of the sample population. The high correlations between sub-scales, the high internal consistency values and unitary factor structure are all consistent with the view that HRQL can be viewed as a single, general construct in hospital patients. It will remain valuable in specific instances to use the domain scales to examine the impact of interventions on particular aspects of HRQL. (14)

Quality of Life: Influencing factors

Two major themes emerged as important influences on HRQL scores in hospital asthma patients- avoidance coping styles, and socio-economic disadvantage. Clinical variables were lesser contributors to the regression models. Mental health was affected by the level of positive evaluations, or satisfaction with asthma, made by people. Self-reported adherence was not an important mediating behaviour through which coping strategies affected HRQL.

Using a small number of items, it was possible to predict the majority of the variance in asthma quality of life, and to predict changes in QOL scores over

12 months. The combination of the 15 psychosocial variables (including the coping styles, economic questions, and self-rating of severity), plus the 22 item MAQLQ-M, along with a query regarding previous emotional counselling (15), would provide an easily administered and interpreted tool to measure disease status, and would also quantify psychosocial distress. (16) Evaluation of this instrument in a prospective manner is an area of potential research.

There was a separation between conventional markers of socio-economic status such as income and education and the variables focusing on the impact of economic disadvantage on asthma, in influencing HRQL. The degree to which economic choices are available and how individuals' and their families make them, clearly impacts heavily on quality of life in asthma patients. The precise mechanisms operating here are not yet fully determined. Some insights were gained from this study. The effects on HRQL of self-efficacy and of an active coping style were confounded by the economic variables in the regression models. The level of perceived social support, which in turn is affected by socio-economic disadvantage, also influenced the effect of active coping on HRQL. Cost barriers are a significant impediment to management in asthma patients. Adequate medical care, as indicated by such measures as the provision of written action plans, intensive medication regimes and good self-management knowledge, was not enough to overcome the effect of economic disadvantage on HRQL.

Quality of Life: Measuring clinically meaningful change

Using patients' global rating of change as a criterion standard, the difference in scores on the HRQL questionnaires that corresponded to the minimally important perceptible difference was determined (MCID). For the MAQLQ-M this also corresponded with the statistically reliable change in scores. However, the greater variance in the SF-36 scores for those people assessing themselves as stable, meant that there was a discrepancy between the mean score of the MCID and the statistically reliable change. This also contributed to the MAQLQ-M being a more powerful and sensitive measure of change. Consequently, the sample sizes needed in research studies to ensure

sufficient power to eliminate Type II errors is greater for the SF-36 than for the MAQLQ-M. That clinical measures such as symptoms and lung function assess different aspects of the asthma experience to HRQL questionnaires was emphasised by this part of the study. There was not a very close relationship between patient-perceived changes of significance in HRQL scores, and changes in symptoms or FEV_1 designated to be of significance.

Quality of Life: Alternative scoring methods

The use of item-response theory methods to score the MAQLQ-M and the PF-10 and MHL scales of the SF-36 confirmed the unidimensional constructs of these scales. The IRT models demonstrated that traditional summative scoring methods did not produce scales at the interval level of measurement. Scales were not equidiscriminating at all levels of health status, ie smaller differences in underlying quality of life were needed in the middle range to produce the same score differences. Coverage by items was less complete at the extremes of HRQL by the MAQLQ-M and both SF-36 scales.

Factors associated with use of health services

Acute use of health services was common amongst this group of hospital clinic patients. Recurrent use of services was also common with nearly half having repeated attendances at emergency departments. Several factors emerged as risk indicators for admissions to hospital. One group of variables related to markers of asthma severity- previous admissions, more frequent asthma attacks, and lower scores on the BREATHLESSNESS sub scale of the MAQLQ-M. Recurrent attendance at emergency departments (ED) was also related to a group of markers of disease severity, including the need for maintenance oral corticosteroids, the need for third-line asthma medications such as theophylline preparations, and previous hospital admissions. Although of those not taking any inhaled corticosteroids (ICS) medication at baseline, 40% were admitted to hospital and 45% had recurrent presentations to casualty, most individuals with frequent symptoms reported taking daily doses of ICS of over 1000/mcg. This suggests that whilst there is potential for reductions in hospital admissions by ensuring appropriate maintenance

medication in a small sub-group of hospital clinic patients, other issues will need to be addressed for major improvements to be made in rates of health service use. Improving other aspects of quality of care may be important, given that reporting not being in possession of a written asthma action plan was associated with a greater risk of admission to hospital.

Psychosocial factors were also important. Using avoidance coping strategies was a significant predictor of admissions and recurrent admissions to hospital. Education level and employment status affected the need to use health services as well. Concerns about costs causing delaying seeking needed care was associated with repeat ED attendances. However, patients using acute services are not necessarily substituting this for help from their general practitioner, as over 45% of those seen more than 6 times over the 12 months for their asthma had admissions to hospital or repeat attendances at EDs.

Self-management Autonomy Preferences

Although enhancing patient self-management in asthma through increased autonomy in decision-making has been promoted widely (17-19), the results of this study indicated that patients do not show strong preferences for having a major role in decision-making. Similar to Gibson et al (20), most subjects from this population favoured at least shared decision-making with their doctors in altering treatment in hypothetical situations.

The psychometric characteristics of the Asthma Autonomy Preference Index (API) have not previously been reported. Factor analysis indicated the presence of two components of the Asthma API. One factor concerned action during a mild-moderate asthma exacerbation and decisions regarding when to initiate contact with medical services. The other factor was composed of items involving identifying possible alternatives and the best therapeutic options, where medical expertise is advantageous. Subjects were more likely to express a desire for independence in decision-making in the "action plan" scenario, than for the "problem-solving" area of management. Decisions about when to seek medical care were felt to be mostly a patient's

prerogative, but when and what treatment should be initiated in a moderate asthma attack were felt to a shared process. The implication of this is that to address the problem of delays in initiating appropriate changes in care in acute attacks two separate but conceptually related areas of decision-making must be considered.

The attitudes of individuals and the approach of the doctor to management were important in predicting autonomy preferences. Individuals who are confident in their ability, and who cope with stresses by seeking out information, formulating plans and viewing these stresses as challenges to be overcome want to retain some control over treatment decisions. Individuals who expressed strong concerns about side effects also said that these concerns prevent them from taking many asthma medications. Concerns about costs were particularly an issue in the exacerbation scenario, emphasising the powerful influence economic circumstances exert over behaviour and attitudes in what may be regarded by clinicians as a relatively straightforward medical situation. It would seem unlikely that patients will enthusiastically initiate increases in medications or seek medical advice if the cost implications of these actions weigh heavily in their assessments. (15) The independent effect of the clinicians' participatory decision-making style is consistent with other research showing the importance of the doctor-patient relationship on patient adherence and behaviour in asthma. (15,21,22)

Measures of clinical status or quality of life were not related to individuals' API scores. Autonomy preferences at baseline did not predict changes in quality of life or health service use over 12 months. This raises questions regarding the importance of the measurement of autonomy preferences in asthma patients. It is possible that a longer time-frame than 12 months is needed to see the effect of this variable on health outcomes, or that its effect is being mediated via other factors such as coping, self-efficacy or adherence.

Physician's participatory decision-making style

The propensity of managing physicians to involve their patients in decisions about treatment and encourage their patients to take control over their

management was correlated with the length of the consultation visit, the length of relationship with that doctor, educational level, age, and patient satisfaction with interpersonal care. Respondents who rated their health as excellent also reported having more participatory visits with their doctors, compared with those rating their health as less good. In a multiple logistic regression analysis, higher physician's Participatory Decision-Making (PDM) style could be predicted from organisational factors only, ie the length of the office visit (> 20 minutes) and the duration of tenure of the physician-patient relationship (> 6 months). The length of time the patient had been attending the hospital clinic was not related to PDM style, suggesting a negative effect of provider switching within the clinic, where patients' see a different doctor at successive visits.

Future research: Methodological issues

The Juniper AQLQ has previously been shown to be more sensitive to within-subject changes than the Living with Asthma Questionnaire. (12) The associations with reference measures of the MAQLQ-M were very similar to that reported elsewhere for the Juniper AQLQ. (9,23) This suggests that the fixed-format MAQLQ-M may be comparable to the Juniper AQLQ as a measure of change, and as a discriminative cross-sectional measure, in asthma patients. Future research is needed to compare the MAQLQ-M and the Juniper AQLQ in different populations to assess the relative validity and responsiveness of these instruments. The advantages in more easily allowing comparisons across populations and patients, and the administrative simplicity of the MAQLQ-M, could potentially make it the instrument of choice in research and clinical settings.

The concerns raised by Simon and colleagues regarding the paradoxical effect of the current scoring methods of the SF-36 component summaries need to be addressed. The similarity of scores across all HRQL scales in this study would suggest that future studies may need to explore alternative scoring methods for the SF-36 summary scales in longitudinal trials on populations of hospital-based asthma subjects. (24) Possibilities would include using positive factor coefficients or a radically altered scoring system

based on item-response methods to achieve different weighting of items and scales.

An evaluation trial using a limited number of items (approximately 40) as a clinical measure of disease status and psychosocial burden in asthma clinics could use such areas as physician behaviour, patient outcomes such as service utilisation and satisfaction, and individual and system costs, as outcomes. The use of this tool as an evaluation measure of intervention trials would assist in determining if interventions can reduce the "bother" of asthma without altering functional status. (25)

The clinical utility of IRT scoring models could be trialed. The effects on clinician decision-making or on intervention outcomes could be compared using IRT and summative scoring methods. The use of IRT methods could be compared with traditional scoring in particular populations, especially those whose health status lies at the edges of the HRQL continuum.

Future work could examine the use of item response theory to calibrate additional items for the HRQL instruments. These could be used to set up item banks for potential use in computerised adaptive testing and to allow better precision for assessing individual HRQL. The combination of large item banks that cover the full range of HRQL calibrated by IRT, along with the computerised adaptive testing would allow the construction of tailored scales for an individual patient. (26,27) This would work by making the second item presented to the patient dependent to the response to the first item, at such a level of "difficulty" that it adds the greatest contribution to measuring the domain. (26) This would continue on with successive items until a preset stopping point was reached. The tailored scales would be different for each patient, but all would assess the construct of asthma-HRQL because the items are all selected from the item bank which has been calibrated using IRT. Further developments would account for a particular individuals circumstances by asking a few identifying questions which would allow items to be tailored for activities or life circumstances. Thus, for example, items relating to "shovelling snow" would not be administered to Queenslanders, or items relating to "lifting" to those with back injuries.

Future research: Psychosocial aspects of asthma

Two major themes relating to psychosocial issues have been identified that have a significant impact on asthma health outcomes. These are personal coping styles, particularly that of avoidance, and socio-economic disadvantage, particularly financial pressures and lower education.

Given the strong association of avoidance coping with HRQL and hospital admissions, further work to delineate how this may operate is of some importance. Avoidance coping may operate negatively at several levels in affecting asthma patients, including sub-optimal use of medications, withdrawal from social contact, and delaying initiating appropriate changes to treatment or in seeking medical help in acute attacks. To more accurately identify what areas of self-management are affected by different coping strategies in an individual would require accurate measurement of disease activity, and also detailed interviews examining patient behaviour during acute exacerbations. Such a process would also help identify the effectiveness of such things as provision of written action plans in different groups stratified by coping styles or socio-economic status or clinical severity. Some form of external assessment of the severity of an exacerbation would also be required. Coping styles and personality traits play complementary roles in how people deal with various situations. (28) The relationships between coping styles, particularly avoidance, and psychiatric problems such as depression and anxiety, warrants further investigation in regard to the impact on asthma HRQL. Estimating coping strategies used by individuals may be a means of selecting which patients are more likely to be either in need of, or likely to benefit from, approaches that focus on areas such as self-regulation. Whether a simple increase in the amount of time spent with the patient can increase both the doctors' tendency to involve patients in their management, patient autonomy, and subsequently patient outcomes, merits further research.

The question of whether the sequences individuals use coping strategies has a major impact on self-management behaviour and subsequently on outcomes is a potential area for investigation. Longitudinal studies adopting a stage-based theoretical approach derived from the trans-theoretical model could be used as a framework for posing questions on coping sequences or hierarchy. The relationship between such concepts as self-identity and role identity, and their influence on coping styles used in response to the stress of chronic asthma could also be examined within this framework. An examination of the conditions, especially socio-economic conditions, under which self-efficacy in asthma may or may not be mutable and the methods for inducing higher levels of self-efficacy under these conditions remain questions of interest for future work. (29)

The stage-based theoretical model and the concept of self-regulation could be used to design interventions designed to alter self-management behaviour. In a manner analogous to smoking-cessation programs, asthma education would be delivered to match the stage or phase of each individual. Thus, those maintaining an attitude of avoidance or refusal to accept the identity of asthma would receive an intervention designed to help reappraisal of the nature of the disease and of individual risk. People contemplating action to take control of their management would receive education and assistance matched to their phase. Success would be measured by advancement along at least one stage or phase.

Behavioural-cognitive interventions are a potential means of reducing 'bother', encouraging reappraisal of asthma and self-management and a more active coping style. (30) Alternative means of delivering such programs would include the use of change agents. Approaches used successfully in other areas include a nurse practitioner or trained health care worker meeting with patients to teach negotiating skills with physicians, to increase appropriate information-seeking and giving within consultations, to increase patient participation in care. (31,32) Focusing interventions on teaching clinicians empathic task-focused communication with patients in the consultation have been used in some areas, but few instances are found in the respiratory literature. Acknowledging patient concerns, particularly medication side-effect

concerns and difficulties in life-style adaptation to medication usage, would appear a critical part of these interventions. The concept of stages of change could provide the framework for these interventions. The patient-partner program as described in the rheumatology literature could be adapted for asthma. (33,34) Trained patients could assist as behavioural models and as identified support figures, either in one-on-one or group settings. These individuals could assist in educating medical students and physicians with regard to the issues of importance to patients, and which education techniques may be effective, particularly with regard to the formal education level of the patient.

Future research: Clinical correlates of HRQL

The strongest correlate of the subjective variables of asthma status with HRQL was the self-rating of severity. How impaired perception of airway obstruction influences an individual's self-rating of severity, and the subsequent effect this may have on their quality of life has not been explored, but could offer interesting insights into how physiology influences handicap.

The longitudinal relationship between psychosocial factors, HRQL, and disease activity, which is a composite entity relating to symptom intensity, airway obstruction and the amount of medication needed to control the condition (35), warrants further study. To accurately assess disease activity is a difficult task. (36) Any attempt requires the use of modern non-invasive measures of physiological status, such as induced sputum analysis (36). Despite much research, the relationship between airway inflammation, airway hyperresponsiveness and functional airway obstruction remains poorly defined. (37) Some authors have suggested it will continue to do so for some time into the future. (37) Potential mechanisms by which psychological stress may influence immune measures has received some attention (38,39), but the picture is far from complete, and the effect of differing coping strategies on this has not been explored. Without some form of objective measurement of inhaler use it will be difficult to accurately know what patients are taking, and the consequences of this usage or non-usage. (40) Longitudinal lung function measurements, preferably using electronic recordings of peak flow or

spirometry, would complete the clinical picture. From there, the relationship between clinical status, with psychosocial circumstances, and handicap, with its social, role and behavioural aspects, encapsulated in quality of life, could be better elucidated. The value of quality of life as an outcome tool in this area of research lies in its potential to evaluate the relative benefits to individuals of asthma control versus the 'bother' to patients of asthma management. (25) Adequately identifying and controlling for psychiatric conditions such as depression or anxiety, possibly by using clinical interviews, is important in helping to clarify the impact of mood on coping mechanisms, and on asthma.

Future research: Socio-economic status

Further work to more accurately define what aspects of costs limit asthma care is needed. Whether this is purely a matter of the expense of medications, or a more complex issue relating to spending priorities and valuing of health, needs to be identified. This may be mediated via under-treatment or inappropriate medication over prolonged periods, or by patients not filling prescriptions or by delays in attending the general practitioner during attacks. The influence of lower education and economic disadvantage may reduce the ability of patients to maximise the benefits of any educational or self-management intervention. Investigating the impact of social factors on successful patient outcomes from self-management programs warrants attention. Investigating if teaching self-management with specific regard to the educational level of the patient, and stressing the area of autonomous decision-making, will improve outcomes is an area for future research.

This research recognises that health services are not disconnected from social conditions. (41) Improved social conditions, promotion of healthy behaviours by individual persons, and universal access to medical care are not alternative but synergistic strategies in the pursuit of health. (41) Some have suggested that to improve health in the population, physicians must serve as advocates for improved social conditions, public health initiatives, general and health education, and behavioural interventions. (42) However, the existence of cost barriers indicates an ongoing disparity of access to care

between rich and poor occurring in a system of ostensibly universal coverage. (43) Further work is required to examine if organisational factors in public hospitals such as increased consultation times, steady tenure of doctor-patient relationships, outreach clinics, organised systems of telephone access to experienced staff, and negligible cost medications, will improve outcomes.

Conclusion

The measurement of health outcomes in asthma remains complex. Psychosocial factors need to be elucidated and controlled for in any trial that reports HRQL outcomes. More complex trial designs should be considered that control for some of these factors at the outset of studies. (44)

The structural constraints upon health behaviours by socio-economic circumstances deserve greater attention in trials of self-management programs and behaviour change interventions. Conversely, to ignore the personal determinants that affect health behaviour may be to miss areas where changes can be made. More generally, the results show that failing to look at the patient in the context of their whole life and considering the socio-economic, psychological and attitudes and beliefs of patients, the current reductions in asthma morbidity and mortality may not continue.

Appendix

The Queen Elizabeth Hospital
Woodville. SA
Thoracic Medicine Unit

ASTHMA STUDY QUESTIONNAIRE

Thank you for agreeing to participate in this study.

We are trying to improve the way we help you manage asthma. The following questions ask you about how asthma affects your life, what you think about your medications and treatment generally, and about what you would do if you were having an asthma attack.

Your answers remain completely confidential. They will not be recorded in the medical case notes.

We will be asking you to repeat the questionnaire in a few months time to see if any changes have occurred over time.

Please take a few minutes to complete the questionnaire now.

THE NEXT QUESTIONS ASK ABOUT WHO YOU FEEL SHOULD BE MAKING DECISIONS ABOUT YOUR ASTHMA TREATMENT.

PLEASE LOOK AT THE FOLLOWING DESCRIPTIONS OF ASTHMA.
IMAGINE THAT ASTHMA IS AFFECTING YOU IN THIS WAY.

FOR EACH STATEMENT PLEASE TICK THE RESPONSE WHICH APPLIES MOST TO YOU.

A. Suppose you have visited your doctor for a routine check-up of your asthma and to obtain prescriptions for your asthma medicines.

WHO SHOULD MAKE THE FOLLOWING DECISIONS?

1. **When the next visit to check your asthma should be?**

2. **Whether you should buy a peak flow meter and use this to check on your asthma?**

3. **Whether you should be seen by a specialist?**

4. **What action you should take if your if your asthma gets worse?**

B. For the last 4 days you have been feeling more wheezy and breathless than usual, and you have found it increasingly difficult to get on with your everyday activities.
Last night you were awakened twice because of asthma and you found it difficult to get back to sleep.
Today you wake earlier than usual and are feeling very breathless.

WHO SHOULD MAKE THE FOLLOWING DECISIONS?

5. **Whether you should be seen by the doctor?**

6. **Whether you should take more Ventolin / Bricanyl?**

7. **Whether you should increase your preventer asthma inhalers (Becotide, Becloforte, Pulmicort, Flixotide)?**

8. **Whether you should take prednisolone or cortisone tablets?**

C. Suppose you had an attack of severe asthma that was not relieved by your inhaler, and you were frightened enough to go to the hospital emergency (casualty) department.
In the emergency department , doctors treat your asthma and you are then taken to the intensive care unit for further treatment.

WHO SHOULD MAKE THE FOLLOWING DECISIONS?

9. **How often the nurses should wake you up to check your temperature and blood pressure?**

10. **Whether you may have visitors aside from your immediate family?**

11. **When you are able to be discharged?**

12. **Whether the nurses should wake you from sleep to give you the nebuliser?**

(Note: Response options for these items were)

You alone	Mostly you	The doctor and you equally	Mostly the doctor	The doctor alone
❑	❑	❑	❑	❑

THE NEXT QUESTIONS CONCERN WHO YOU FEEL SHOULD BE MAKING THE DECISIONS ABOUT YOUR ASTHMA IN GENERAL.

PLEASE READ THE FOLLOWING STATEMENTS AND TICK THE RESPONSES THAT APPLY MOST CLOSELY TO YOU.

13. **The important medical decisions about your asthma should be made by your doctor, not you**

14. **You should go along with your doctors advice even if you disagree with it?**

15. **When in hospital for your asthma, you should not be making decisions about your care?**

16. **You should feel free to make decisions about everyday problems with asthma?**

17. **If you were sick, as your asthma became worse you would want your doctor to take greater control?**

18. **You should decide how frequently you need a check-up for your asthma?**

(Note: Response options for these items were)

Strongly agree	Mostly agree	Unsure	Mostly disagree	Strongly disagree
❑	❑	❑	❑	❑

Attitudes to medication

These next set of questions are to find out about how you feel about asthma and its treatment.

1. Which medications do you think are useful in controlling your asthma?

Becotide	**Yes / No / Don't know**
Becloforte	**Yes / No / Don't know**
Pulmicort	**Yes / No / Don't know**
Ventolin / Respolin	**Yes / No / Don't know**
Bricanyl	**Yes / No / Don't know**
Atrovent	**Yes / No / Don't know**
Theophylline	**Yes / No / Don't know**
Prednisolone/Cortisone	**Yes / No / Don't know**
Serevent	**Yes / No / Don't know**
Flixotide	**Yes / No / Don't know**
Intal	**Yes / No / Don't know**
Other	**Yes / No / Don't know**
(Please write_____)	

2. Some people decide, for all sorts of reasons, not to take prescribed medications. Are there any prescribed medications that you have decided against taking?

Becotide	**Yes / No**
Becloforte	**Yes / No**
Pulmicort	**Yes / No**
Ventolin / Respolin	**Yes / No**
Bricanyl	**Yes / No**
Atrovent	**Yes / No**
Theophylline / Theodur	**Yes / No**
Prednisolone / Cortisone	**Yes / No**
Serevent	**Yes / No**
Flixotide	**Yes / No**
Intal	**Yes / No**
Other	**Yes / No**
(Please write_____)	

3. How often do concerns about medication side effects prevent you from taking asthma medication? **(Please circle one answer)**

Never
Rarely
Sometimes
Frequently
Most of the time

Could you elaborate on these?

_____
_____
_____
_____

Do you think your preventer medication (Brown, yellow or orange) should be taken-

Regularly	**Yes / No / Don't know**
As a short course when you are unwell	**Yes / No / Don't know**
Only as needed	**Yes / No / Don't know**

Do you think your reliever medication (blue) should be taken-

Regularly	**Yes / No / Don't know**
As a short course when you are unwell	**Yes / No / Don't know**
Only as needed	**Yes / No / Don't know**

Do you think you take your medication as your doctor prescribed it-
(Please circle one answer)

Always
Most of the time
Sometimes
Rarely
Never

Have you ever been given a demonstration by anyone on how to use your asthma treatment devices (eg puffers,nebulisers,peak flow meters)?

Yes / No

Do you think any other medications, therapies or techniques are useful in controlling your asthma (eg herbal medicines, breathing techniques)?

Yes / No

). If Yes, which treatments?

_____
_____
_____
_____

THESE QUESTIONS ASK ABOUT YOUR ASTHMA SYMPTOMS.
PLEASE CIRCLE AS APPROPRIATE FOR YOU

OVER THE PAST FOUR WEEKS-

1. Have you had any problems at night due to asthma (eg coughing, wheezing, tightness in the chest or feeling short of breath)? **Yes / No**

2. How often?-
   - ❑ More than once a night
   - ❑ Most nights
   - ❑ once a week
   - ❑ once a month
   - ❑ never

3. Have you had any problems in the morning due to asthma (eg coughing,wheezing, tightness in the chest,or feeling short of breath)? **Yes / No**

4. How often?- (please choose one)
   - ❑ Every morning
   - ❑ Most mornings
   - ❑ once a week
   - ❑ once a month
   - ❑ never

5. Have you been limited in what you could do? (Please choose one of these options)
   - ❑ Limited getting dressed
   - ❑ Limited walking on the flat
   - ❑ Limited hurrying on the flat
   - ❑ Limited walking uphill or upstairs
   - ❑ Limited playing sport or doing exercise
   - ❑ No limitations at all

OVER THE PAST 3 MONTHS-

6. How many courses of prednisolone (cortisone, steroid) tablets have you taken for asthma? _____

7. How many times have you had an attack of asthma that was so bad that you needed to go to the hospital emergency (casualty) department for asthma treatment? _____

8. How many times have you had an attack of asthma that was so bad that you had to be admitted to a hospital ward and stayed there for at least one night for asthma treatment?". _____

9. How often have you had attacks of asthma? (please choose one)

- ❑ Persistently
- ❑ More than weekly
- ❑ More than monthly
- ❑ More than 3 times / year
- ❑ Less than 3 times / year
- ❑ Never

10. How often have you needed to see your GP (local doctor) for your asthma? _____

11. How many days have you been absent from school or work because of asthma? _____

12. How many days have you been limited by asthma in doing your usual daily activities? _____

OVER THE PAST 5 YEARS-

13. How many times have you been admitted to hospital for asthma treatment? _____

14. How many times have you been admitted to the intensive care unit(ward)? _____

OVERALL, OVER THE PAST YEAR-

15. Overall. How do you rate your asthma? (please choose one)

- ❑ Severe
- ❑ Moderate
- ❑ Mild
- ❑ Not a problem

16. Do you feel your asthma is generally (please choose one)

- ❑ Getting better?
- ❑ About the same?
- ❑ Getting worse?

THE FOLLOWING QUESTIONS ARE ABOUT YOUR ASTHMA TREATMENT

17. What medications (puffers/sprays/tablets) are you taking for asthma today, and how much of them do you take everyday?

_____

_____

_____

18. How often do you need to buy a replacement reliever (blue) puffer (Ventolin/Respolin/Bricanyl) _____

19. How often do you use your reliever (blue) puffer (Ventolin/Respolin/Bricanyl)? _____

20. We can all forget to take medication. Do you ever miss a dose of your preventer puffer? (Becotide/Becloforte/Pulmicort/Fluticasone)

- ❑ Most of the time
- ❑ Two or three times a week
- ❑ Weekly
- ❑ Occasionally
- ❑ Never forget

21. Do you have a plan of what to do if your asthma gets worse? **Yes / No**

22. If yes, is it a written plan given to you by your doctor? **Yes / No**

23. What does it involve?

- ❑ Contact GP
- ❑ Increase medications

(Which ones? _____
_____)

- ❑ Start oral steroids (cortisone or prednisolone tablets)

(Anything else? _____
_____)

24. What would you do if you were unwell due to asthma?

_____
_____

25. What would you do if you were using your reliever (blue) puffer more than 6 times a day? (or your peak flow was less than 60% of your best) _____
_____

26. What would you do if you were using your reliever (blue) puffer more than every 2 hours?
(or your peak flow was less than 40% of your best) _____
_____

27. When do you think your preventer puffer should be taken? (please choose one)

- ❑ Regularly
- ❑ When you're sick
- ❑ As needed

34. Do you feel your asthma is more of a problem in

- ❑ Summer
- ❑ Autumn
- ❑ Winter
- ❑ Spring
- ❑ Season doesn't matter

31. Do you smoke? **Yes / No**

32. If Yes, How many per day? _____

33. Does anyone else smoke inside your house regularly? **Yes / No**

35. Do you have any other medical problems? **Yes / No**

36. What are they?

_____
_____
_____
_____

37. Do you take any other medicines for these problems? **Yes / No**

38. What are they?

_____
_____
_____
_____
_____

39. How long have you had asthma? (in years) _____

40. Does anyone else in your family have asthma? **Y / N**

41. Do you see anyone else for your asthma?

- ❑ Specialist
- ❑ Pharmacist
- ❑ Naturopath
- ❑ Other
  Who? _____
  _____

42. Do you have a peak flow meter at home? **Y / N**

If Yes, how often do you use it? _____

43. Have you ever had professional counselling, or seen a psychiatrist? **Y / N**

ASTHMA QUALITY OF LIFE QUESTIONNAIRE

Thank you for taking this questionnaire. It is part of a research project to learn about the way asthma affects people's lives. All your answers will be treated confidentially.

The information will not be entered into your medical record.

What follows is a series of statements describing the way asthma or its treatment affects some people. You are asked to tick the response to each statement which closely applies to apply you **over the past four (4) weeks.**

The following response options apply to each question: "All of the time", "Most of the time", "A good bit of the time", "Some of the time", "A little of the time", "Hardly any of the time", "None of the time",

1. I have been troubled by episodes of shortness of breath.
2. I have been troubled by wheezing attacks.
3. I have been troubled by tightness in the chest.
4. I have been restricted in walking down the street on level ground because of asthma.
5. I have been restricted in doing light housework because of asthma.
6. I have been restricted in walking up hills because of asthma.
7. I have been restricted in doing heavy housework because of asthma.
8. I have felt tired or had a general lack of energy because of asthma.
9. I have been unable to sleep at night because of asthma.
10. I have felt sad or depressed because of asthma.
11. I have felt frustrated with myself because of asthma.
12. I have felt anxious, under tension or stressed because of asthma.
13. I have felt that asthma is preventing me from achieving what I want from life.
14. Asthma has interfered with my social life.
15. I have been limited in going to certain places because they are bad for asthma.
16. I have been limited in going to certain places because I have been afraid of getting an asthma attack and not be able to get help.
17. I have been restricted in the sports, hobbies or other recreations I can engage in because of my asthma.
18. I felt generally restricted because of asthma.
19. I have felt that asthma is controlling my life.
20. I have been worried about my present or future health because of asthma
21. I have worried about asthma shortening my life.
22. I have felt dependant on my asthma sprays
23. I have felt asthma has impaired my performance at work.*
24. I feel I have good control over my asthma.*

Medication dislikes

I dislike using medication such as inhalers in front of other people.
I dislike taking medication every day.
I dislike taking oral prednisolone (steroid or cortisone) tablets for my asthma.
I dislike taking an inhaled steroid (preventer) medication for my asthma.

Adherence

I had a hard time doing what the doctor suggested I do.
I found it easy to do the things my doctor suggested I do.
I followed my doctor's suggestions exactly.
I was unable to do what was necessary to follow my doctor's treatment plans.
Generally speaking, how often were you able to do what the doctor told you.

Active coping

I thought about what I needed to do for my asthma.
I reminded myself that things could be worse.
If I am unwell I talk to the professionals (nurse, doctor) about my asthma.
I have become more informed about my asthma.
I made a plan of action for my asthma.
I have talked to my friends or relatives about my asthma.

Avoidance coping

I have slept more than usual
I have decided to spend more time alone.
I have become withdrawn from other people.
I have tended to take it out on other people.
I have made myself feel better by eating, smoking or drinking.
I have hoped for a miracle to make me better.

Denial

Except for my illness, I do not have any problems in my life.
Do you have any personal worries which are not caused by physical illness.
Do you have any financial problems.
All my worries would be over if I were physically healthy.
Do you have any family problems.

Note:
1. The questionnaire presented to study subjects did not identify scales by name. This is done here for the convenience of readers in order to more easily identify the various scales and their component items.
2. Questions 23 and 24 above were items included in the original item pool from which the final AQLQ instrument was developed. They were included in the current study as items of interest, but were not scored as part of the MAQLQ-M scores.

SATISFACTION SURVEY

Please spend a few moments thinking about your visit to outpatients and then answer the following questions by CIRCLING THE NUMBER IN EACH LINE.

	POOR	FAIR	GOOD	VERY GOOD	EXCELLENT
1. Explanation by the doctor of what was done for you.	1	2	3	4	5
2. How easily you communicated with the doctor.	1	2	3	4	5
3. The skills of the doctor. (knew what s/he was doing, thoroughness)	1	2	3	4	5
4. The equipment in the office.	1	2	3	4	5
5. The amount of time you spent with the doctor.	1	2	3	4	5
6. The confidence you have in the treatment you received.	1	2	3	4	5
7. How comfortable you felt with the doctor this visit.	1	2	3	4	5
8. The privacy of your medical records.	1	2	3	4	5
9. The manner of the doctor (enthusiasm, friendliness, courtesy)	1	2	3	4	5
10. The amount of attention the doctor gave you.	1	2	3	4	5
11. The visit overall	1	2	3	4	5
12. In general, would you say your health is	1	2	3	4	5

13. If there were a choice between treatments, would your doctor ask you to help make the decision?

Definitely Yes	Probably Yes	Maybe	Probably No	Definitely No

14. How often does your doctor make an effort to give you some control over your treatment?

Very Often	Often	Some of the Time	Occasionally	Never

15. How often does your doctor ask you to take some of the responsibility for your treatment?

Very Often	Often	Some of the Time	Occasionally	Not at All

16. How long was your visit (ie the time spent with the doctor)?

Less than 5 minutes	6-10 minutes	11-20 minutes	21-30 minutes	30 minutes or longer

17. Over what time have you been coming to the hospital for your chest problems?

First visit	Less than 6 months	6 months to 1 year	1 year to 5 years	5 years or longer

18. Over what time have been seeing the doctor you saw today?

First visit	Less than 6 months	6 months to 1 year	1 year to 5 years	5 years or longer

19. What is your age? _____ **years**

20. What is your gender? **Male** **Female**

21. Where were you born?

a. Australia - Non Aboriginal
b. Australia - Aboriginal
c. United Kingdom
d. Italy
e. Elsewhere _____ (Please specify)

22. Of the following categories what was the highest level of education you reached?

a. never went to school
b. completed primary school
c. 3 years or less of secondary school
d. 4 or more years of secondary school
e. some tertiary or further education
f. completed a tertiary or further education course.

23. What is your marital status?

a. Married / Defacto / Partner
b. Separated / Divorced
c. Widowed
d. Never married / single

This part of the questionnaire asks you about your **general health**, how you feel and how well you are able to do your usual activities.
Please answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. **In general,** would you say your health is:

	(circle one)
Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

2. **Compared to one year ago,** how would you rate your health in general **now**?

	(circle one)
Much better than one year ago	1
Somewhat better now than one year ago	2
About the same as one year ago	3
Somewhat worse now than one year ago	4
Much worse than now than one year ago	5

3. The following questions are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, **how much**?

(circle one number on each line)

ACTIVITIES	Yes, Limited a lot	Yes, Limited a little	No, Not Limited at all
a. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	1	2	3
b. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf.	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing **several** flights of stairs	1	2	3
e. Climbing **one** flight of stairs	1	2	3
f. Bending, kneeling or stooping	1	2	3
g. Walking **more than one kilometre**	1	2	3
h. Walking **half a kilometre**	1	2	3
i. Walking **100 metres**	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the **past four weeks,** have you had any of the following problems with your work or other regular daily activities **as a result of your physical health?**

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities.	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example it took extra effort)	1	2

5. During the **past four weeks,** have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. During the **past 4 weeks,** to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one number only)

Not at all	**1**
Slightly	**2**
Moderately	**3**
Quite a bit	**4**
Extremely	**5**

7. How much **bodily pain** have you had during the **past 4 weeks?**

(circle one number only)

No bodily pain	**1**
Very mild	**2**
Mild	**3**
Moderate	**4**
Severe	**5**
Very severe	**6**

8. During the **past 4 weeks,** how much did **pain** interfere with your normal work (including both work outside the home and housework)?

(circle one number only)

Not at all	**1**
A little bit	**2**
Moderately	**3**
Quite a bit	**4**
Extremely	**5**

9 These questions are about how you feel and how things have been with you **during the past 4 weeks.**
For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks-**

(circle one number on each line)

	All of the time	**Most of the time**	**A Good bit of the time**	**Some of the time**	**A little of the time**	**None of the time**
a. Did you feel full of life?	**1**	**2**	**3**	**4**	**5**	**6**
b. Have you been a very nervous person?	**1**	**2**	**3**	**4**	**5**	**6**
c. Have you felt so down in the dumps that nothing could cheer you up?	**1**	**2**	**3**	**4**	**5**	**6**
d. Have you felt calm and peaceful?	**1**	**2**	**3**	**4**	**5**	**6**
e. Did you have a lot of energy?	**1**	**2**	**3**	**4**	**5**	**6**
f. Have you felt down?	**1**	**2**	**3**	**4**	**5**	**6**
g. Did you feel worn out?	**1**	**2**	**3**	**4**	**5**	**6**
h. Have you been a happy person?	**1**	**2**	**3**	**4**	**5**	**6**
i. Did you feel tired?	**1**	**2**	**3**	**4**	**5**	**6**

10. During the **past 4 weeks,** how much of the time has you **physical health or emotional problems** interfered with your social activities (like visiting friends, relatives, etc.)?

(circle one number only)

All of time	**1**
Most of the time	**2**
Some of the time	**3**
A little of the time	**4**
None of the time	**5**

11. How **TRUE** or **FALSE** is **each** of the following statements for you?

(circle one number on each line)

	Definitely true	**Mostly true**	**Don't know**	**Mostly False**	**Definitely False**
a. I seem to get sick a little easier than other people	**1**	**2**	**3**	**4**	**5**
b. I am as healthy as anybody I know	**1**	**2**	**3**	**4**	**5**
c. I expect my health to get worse	**1**	**2**	**3**	**4**	**5**
d. My health is excellent	**1**	**2**	**3**	**4**	**5**

HERE ARE SOME STATEMENTS ABOUT YOUR LIFE IN GENERAL.
PLEASE SHOW HOW MUCH YOU AGREE OR DISAGREE WITH EACH STATEMENT.

1. Being ill has made me value my life more than I used to.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

2. If you don't have your health you don't have anything.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

3. I enjoy my life despite my problems.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

4. There are many things I care about more than my health.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

5. My illness has shown me the value of friendship.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

6. Good health is of only minor importance in a happy life.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

7. When I feel well, I feel really happy.

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

8. **There is nothing more important than good health.**

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

9. **My relatives really care about my problems.**

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

10. **My illness has helped me learn about my self.**

Strongly Disagree	Mostly Disagree	Partly Disagree	Unsure	Partly Agree	Mostly Agree	Strongly Agree
❑	❑	❑	❑	❑	❑	❑

(Note: Q1,3,5,7,9,10 comprised the Satisfaction with Illness scale.
Q2,4,6,8 were the Health as a Value scale.)

BELOW ARE A FEW STATEMENTS ABOUT YOUR RELATIONSHIPS WITH OTHERS. PLEASE SHOW HOW MUCH EACH STATEMENT IS TRUE OR FALSE FOR YOU.

	Definitely True	**Mostly True**	**Don't Know**	**Mostly False**	**Definitely False**
11.	**I am always courteous even to people who are disagreeable.**				
12.	**There have been occasions when I took advantage of someone.**				
13.	**I sometimes try to get even rather than forgive and forget.**				
14.	**I sometimes feel resentful when I don't get my own way.**				
15.	**No matter who I'm talking to, I'm always a good listener.**				

Note: Responses options for these items were:

Definitely True	**Mostly True**	**Don't Know**	**Mostly False**	**Definitely False**

Note: Questions 11-15 comprised the Socially Desirable Response Set.

ASTHMA STUDY QUESTIONNAIRE

1.What is your marital status?

- ❑ Married
- ❑ Defacto / Partner
- ❑ Separated
- ❑ Divorced
- ❑ Widowed
- ❑ Never married / single

2. Does **anyone in the household** currently do any **paid** work at all in a job, business or farm?

❑ Yes ❑ No(go to question 5)

3. Do **you** do currently do any **paid** work at all in a job, business or farm?

❑ Yes ❑ No(go to question 5)

4. In the main job held last week, what was your occupation?

5. What is your main source of income?

- ❑ Wages / Salary
- ❑ Department of Social Security
- ❑ Superannuation / Income from assets
- ❑ Worker's compensation
- ❑ Partner's / Family income
- ❑ Austudy
- ❑ Other - specify _____

6. Of the following categories what was the highest level of education you reached?

- ❑ never went to school
- ❑ some primary school
- ❑ completed primary school
- ❑ 3 years or less of secondary school
- ❑ 4 or more years of secondary school
- ❑ some tertiary or further education
- ❑ completed a tertiary or further education course.

7 What is your total **gross** annual household income (you and your partner only) or total individual income (if living alone)?
Please count **all income** including family allowance, pensions, unemployment benefits, student allowance, maintenance (child support),worker's compensation, superannuation, wages, salary, overtime, dividends, rents received, business or farm income (less operating expenses), and interest received.

Do **not take out** tax, superannuation or health insurance.

- ❑ Less than $5,000 per year (less than $96 per week)
- ❑ $5,000 - $8,000 per year ($97 - $154 per week)
- ❑ $8,001 - $12,000 per year ($155 - $230 per week)
- ❑ $12,001 - $20,000 per year ($231 - $385 per week)
- ❑ $20,001 - $30,000 per year ($386 - $577 per week)
- ❑ $30,001 - $50,000 per year ($578 - $961 per week)
- ❑ $50,001 - $80,000 per year ($962 - 1539 per week)
- ❑ >$80,000 per year (>$1539 per week)

8. How many other people **usually** live in your home?

- ❑ number

9. Can you please give the following details of any dependent children living at home.

Child no.	Sex.	Age.	Has Asthma,Yes/No
1.			
2.			
3.			
4.			

10. Which of the following best describes your living situation?

- ❑ Housing Trust rental
- ❑ Private rental
- ❑ Living with family / friends
- ❑ Own house, with mortgage
- ❑ Own house, no mortgage
- ❑ Other. Please specify _____

11. In which country were you born?

- ❑ Australia - non-Aboriginal
- ❑ Australia - Aboriginal
- ❑ United Kingdom or Ireland
- ❑ Italy
- ❑ Other - specify _____

18. Over the past four weeks have you been **absent from school or work** because of asthma?

Days absent from work _____
Days absent from school _____

19. Over the past four weeks has your **performance at school or work** been affected by asthma?

Days affected at work _____
Days affected at school _____

20. Over the past four weeks have you been unable to work at **household tasks** because of asthma?

Days affected _____

21. Have you had to **change sports or recreations** because of asthma, and if so have these caused extra costs?

Please specify _____
_____

22. Do you have **private medical insurance?**

❑ Yes ❑ No

If Yes, how much does that cost per year? _____
If you did not have asthma, would you continue with private insurance?

❑ Yes ❑ No

23. Over the past four weeks has the **cost prevented you from obtaining any asthma care** for yourself that was needed?

❑ Yes ❑ No

24. Over the past four weeks has the **cost caused you to delay or avoid seeking any asthma care** for yourself that you would otherwise have needed?

❑ Yes ❑ No

25. Over the past four weeks has **concern about missing work caused you to delay or avoid seeking any asthma care** for yourself that you would otherwise have needed?

❑ Yes ❑ No

26. Have you experienced any financial difficulties over the past year?

❑ Yes ❑ No

27. Do you have someome you feel you can confide in?
❑ Yes ❑ No

28. Do you have someone who makes you feel needed?
❑ Yes ❑ No

29. Do you have someone with whom you share common interests?
❑ Yes ❑ No

30. Do you have someone who comes to visit you at home?
❑ Yes ❑ No

31. Do you go out to visit others?
❑ Yes ❑ No

32. Do you go on outings or to social gatherings with others?
❑ Yes ❑ No

33. Do you attend church or any church groups or any clubs or other social organizations?
❑ Yes ❑ No

Note: Questions 27-33 comprised the Social Support scale.

Overall, over the past four weeks, has their been **any change in your asthma**? Do you feel your asthma has been:

- ❑ Worse
- ❑ About the same
- ❑ Better

If your asthma has been **worse**, **how much worse** has it been?

- ❑ Almost the same, hardly any worse at all
- ❑ A little worse
- ❑ Somewhat worse
- ❑ Moderately worse
- ❑ A good deal worse
- ❑ A great deal worse
- ❑ A very great deal worse

If your asthma has been **better**, **how much better** has it been?

- ❑ Almost the same, hardly any better at all
- ❑ A little better
- ❑ Somewhat better
- ❑ Moderately better
- ❑ A good deal better
- ❑ A great deal better
- ❑ A very great deal better

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Chapter 5: *Predicting health-related quality of life status in asthma.*

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Chapter 10: *Conclusions*

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