Universidade do Minho
Escola de Ciências da Saúde

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Patient enablement and the management of asthma: a study in family practice

Capacitação dos doentes e gestão da asma: um estudo em medicina geral e familiar

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Tese de Doutoramento em Medicina
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DECLARAÇÃO

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Abstract

Background

Asthma is a common condition in general practice but is frequently under-diagnosed. There is wide variation in the reported incidence and prevalence rates of asthma but these rates are believed to be increasing. Research on the magnitude of this problem has met with methodological obstacles because it has been difficult to define and diagnose asthma in epidemiological terms.

There is evidence that the control of asthma involving self-assessment by patients and a stronger doctor-patient relationship can improve compliance to therapeutic plans and lead to better outcomes for patients. Evidence is lacking on the influence of the level of patient empowerment on the quality of life and level of control of asthma. The objectives of the three studies in the present thesis were to assess how physicians in a sentinel practice network perform using standardized diagnostic criteria, to estimate the true prevalence of asthma by gender and age groups in the population of the area covered by one urban Health Centre in Portugal, to assess the severity of asthma, medication use, asthma control, the level of patient enablement and the quality of life in a population of asthmatic patients treated in primary care, and to study the relationship between enablement and the quality of life of asthma patients.

Methods

In the first of three studies conducted for this thesis the incidence of asthma was calculated. Patients consulting physicians from the Portuguese Sentinel Practice Network with complaints suggestive of asthma were enrolled in the study over a four year period. Frequencies of symptoms and diagnoses of asthma were tabulated. Diagnostic accuracy was computed by dividing the rate of asthma diagnosis by the true rate using established diagnostic criteria.

In the second survey, an observational study was conducted in 2009 at the Horizonte Family Health Unit in Matosinhos, Portugal to calculate the prevalence of asthma. A random sample of 590 patients, stratified by age and gender was obtained from the practice database of registered patients. Data was collected using a patient questionnaire based on respiratory symptoms and the physician's best knowledge of the patient's asthma status. The prevalence of asthma was calculated by age and gender.

The third survey was a cross-sectional study conducted in an urban population in northern Portugal to assess the relationships between patient empowerment, asthma control and quality of life. Data were collected from both clinical records and questionnaires administered to a

stratified random sample of asthma patients treated in this clinic. The patient enablement instrument (PEI) was used to assess enablement and the asthma quality of life questionnaire (AQLQ) was used to assess quality of life. Asthma control was assessed using the asthma control test (ACT). Pulmonary function was assessed by measuring peak expiratory flow (PEF) and forced expiratory volume at one second (FEV1). The associations between patient empowerment, asthma control and quality of life were tested using linear and logistic regression models.

Results

In the first study 43 physicians followed 32,103 patients for 4 years and diagnosed asthma in 310 patients. The diagnosis was confirmed in 260 cases giving a true incidence rate of 2.02/ 1000/ year (95% confidence interval 2.12 to 2.46) and an accuracy of diagnosis of 84%.

In the second study, data were obtained from 576 patients with a 97.6% response rate. The mean age for patients with asthma was 27.0 years (95% CI: 20.95 to 33.16). Asthma was diagnosed in 59 persons giving a prevalence of 10.24% (95% CI: 8.16 to 12.32). There was no statistically significant difference in the prevalence of asthma by gender.

The third study included 180 patients. 68% of the patients were female. Over half of the patients (57%) had forms of persistent asthma and 43% had intermittent asthma. The mean patient enablement (PEI) scores were significantly higher for patients with intermittent asthma compared to those with persistent forms ($p<0.01$). There was a strong and statistically significant correlation between asthma control and quality of life ($r^2 =0.64$). A weak correlation between patient enablement and asthma control and quality of life was found.

Discussion

Asthma incidence in the Portuguese population in the first study approaches published rates. The prevalence of asthma found in the second study was higher than that found in some studies, though lower than that found in other studies. The findings of the third study confirm the correlation between good asthma control and quality of life. The finding of a weak correlation between scores on the patient enablement instrument and asthma control requires further study to determine if interventions to improve patient empowerment can improve asthma outcomes

Conclusions

Asthma is a common problem in general practice in Portugal. Adherence to international diagnostic guidelines can improve the rates of diagnosis. Adherence to therapeutic guidelines can improve asthma control and quality of life for patients. Attention to patient enablement may also have a role to play in the care of asthma patients.

Resumo em Português

Capacitação dos doentes e gestão da asma: um estudo em medicina geral e familiar

Introdução

A asma é frequentemente sub-diagnosticada existindo grande variação nas taxas de incidência e prevalência que se pensa estarem a aumentar, mas a investigação sobre a sua magnitude tem encontrado obstáculos metodológicos, uma vez que tem sido difícil de definir e diagnosticar asma em termos epidemiológicos. Existe evidência de que o controlo da asma envolvendo auto-avaliação pelos doentes e uma forte relação médico-doente podem melhorar a adesão aos planos terapêuticos e levar a melhores resultados. Há pouca evidência sobre a influência do nível de capacitação do doente sobre a qualidade de vida e o nível de controle da asma. Os objectivos dos estudos incluídos na presente tese foram: avaliar como os médicos de uma rede sentinela diagnosticam asma usando critérios padronizados de diagnóstico, estimar a prevalência de asma por sexo e grupo etário na população de um Centro de Saúde urbano em Portugal, avaliar a gravidade da asma, o uso de medicamentos, o controle da asma, o nível de capacitação do doente e a qualidade de vida numa população de doentes asmáticos em cuidados primários e estudar a relação entre capacitação e qualidade de vida nestes doentes.

Métodos

No primeiro estudo da tese calculou-se a incidência de asma. Os doentes que consultaram um dos médicos da Rede Médicos Sentinela com queixas sugestivas de asma foram incluídos no estudo por um período de quatro anos. As frequências de sintomas e os diagnósticos de asma foram calculados. A precisão diagnóstica foi calculada dividindo-se a taxa de diagnóstico de asma pela taxa real usando critérios diagnóstico estabelecidos.

O segundo trabalho foi um estudo observacional tendo sido realizado em 2009 na Unidade de Saúde Familiar Horizonte, em Matosinhos. Foi obtida uma amostra aleatória de 590 pessoas, estratificada por idade e sexo a partir da base de dados de inscritos na USF. Os dados foram obtidos através de questionários dirigidos a doentes e a médicos baseados na presença de sintomas respiratórios e no melhor conhecimento do médico do estado de asma do paciente. A prevalência de asma foi calculado por idade e sexo.

O terceiro estudo foi um estudo transversal realizado numa população urbana no norte de Portugal. Os dados foram recolhidos a partir dos registos clínicos e de questionários aplicados a uma amostra aleatória estratificada de pacientes com asma tratados na USF. O *Patient Enablement Instrument* (PEI) foi usado para avaliar a capacitação e o *Asthma Quality of Life*

Questionnaire (AQLQ) foi usado para avaliar a qualidade de vida. O controlo da asma foi avaliado pelo Teste de Controle da Asma (ACT). A função pulmonar foi avaliada pelo débito expiratório máximo instantâneo (PEF) e o volume expiratório forçado no primeiro segundo (FEV1). As associações entre capacitação do doente, o controle da asma e a qualidade de vida foram testados usando modelos de regressão linear e logística.

Resultados

No primeiro estudo 43 médicos seguiram 32.103 utentes durante quatro anos tendo diagnosticado asma em 310. O diagnóstico foi confirmado em 260 casos, obtendo-se assim uma taxa de incidência de 2,02 /1000 /ano (IC 95%: 2,12-2,46) e uma precisão de diagnóstico de 84%. No segundo estudo os dados foram obtidos a partir de 576 pacientes (97,6% taxa de resposta). A idade média dos doente com asma foi 27,0 anos (IC 95%: 20,95-33,16). Foi diagnosticada asma a 59 pessoas dando uma prevalência de 10,24% (IC 95%: 8,16-12,32). Não houve diferenças estatisticamente significativas na prevalência de asma por sexo. O terceiro estudo incluiu 180 doentes, 68% do sexo feminino. Mais de metade dos doentes (57%) tinham formas de asma persistente e 43% intermitente. As pontuações médias do PEI foram significativamente maiores em doentes com asma intermitente em comparação com as formas persistentes ($p<0,01$). Observou-se uma correlação forte e estatisticamente significativa entre o controle da asma e qualidade de vida ($r^2=0,64$). Observou-se uma fraca correlação entre a capacitação dos doentes e controlo da asma e qualidade de vida.

Discussão

A incidência de asma é semelhante à existente na literatura se forem utilizados critérios consensuais. A prevalência de asma encontrada foi maior do que a de alguns estudos, embora menor que a encontrada noutros. As conclusões confirmam a correlação entre bom controlo da asma e qualidade de vida. A fraca correlação entre a pontuação no PEI e o controlo da asma requer um estudo mais aprofundado para determinar se as intervenções para melhorar a capacitação do doente conseguem melhorar os resultados em saúde.

Conclusões

A asma é um problema comum em medicina geral e familiar em Portugal. A adesão a normas de orientação internacionais pode melhorar as taxas de diagnóstico. A adesão às recomendações terapêuticas pode melhorar o controle da asma e qualidade de vida para os doentes. A atenção para a capacitação pode ter um papel a desempenhar nos cuidados a doentes com asma.

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List of abbreviations and acronyms used:

ACQ	Asthma Control Questionnaire
ACT	Asthma Control Test
ANOVA	Analysis of variance
APMCG	Associação Portuguesa dos Médicos de Clínica Geral, Portuguese Society of Family Practice
CARAT	Control of Allergic Rhinitis and Asthma Test
EQLAP	Enablement and quality of life in asthma patients
FEV1	Forced Expiratory Volume in 1 second
GARD	Global Alliance against Chronic Respiratory Diseases
GINA	Global Initiative for Asthma
GP	General Practitioner
GRESP	Respiratory Group within the Portuguese Society of Family Practice
IPCRG	International Primary Care Respiratory Group
ISAAC	International Study of Asthma and Allergies in Childhood
Mini-AQLQ	Mini Asthma Quality of Life Questionnaire
mPEI	Modified Patient Enablement Instrument
OR	Odds Ratio
PEF	Peak Expiratory Flow
PSPN	Portuguese Sentinel Practice Network (Médicos Sentinela)
ROC	Receiver Operating Curve
WHO	World Health Organisation
WONCA	World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians

Most doctors have learnt to treat their patients not as irresponsible children but as adult fellow citizens. Old fashioned mystery men are at last disappearing. Perhaps we might even start taking primary care seriously.

Julian Tudor Hart. *BMJ 1998;317:1*

Introduction

Prologue

Family medicine covers a wide range of subjects, ranging from preventive care to the management of common and acute conditions. However, a considerable amount of the time spent in practice is used to care for patients with chronic conditions. Being a family physician in practice for more than twenty eight years, the management of chronic diseases has slowly become the main focus of my attention.

With time, family physicians understand that the burden of chronic diseases in clinical practice is such that new models of care are needed. The strategies to deal with the most prevalent chronic conditions in the community require a knowledgeable family doctor, a well trained and structured health care team, motivated professionals, a national strategy for the condition and the enablement of patients and their families to understand and deal adequately with the different phases of the disease.

Asthma is a frequent problem in the community. It offers one of the most interesting models of study, reflection and research for family doctors, because of its variety of shapes, different levels of severity, a wide age range, from the very young to the very old and the fact that in the last decade clinicians are able to offer much better treatment options with a higher level of control of the disease and a superior quality of life.

Fourteen years ago, realising that many patients with asthma were having a less than satisfactory level of control than would be expected, I joined the Portuguese Global Initiative for Asthma (GINA) network. Slowly I became more and more interested in spreading the existing guidelines among health professionals and in studying asthma in the community and in my practice.

Since 2006 I gradually became more involved with the International Primary Care Respiratory Group and its Research Sub-Committee in which I have been working since 2008.

Considering the need to understand how to better manage chronic diseases, the special features of asthma and the professional challenges that I met in the last decade, asthma emerged as a natural field of research and academic development. I am happy to have had this opportunity as I feel that today I am more capable of caring for my patients with asthma and have also been able to encourage younger researchers, both medical students and registrars, to deepen their knowledge and initiate research in this field.

Introduction

Chronic disease in the context of family medicine

Definition of chronic disease

Chronic disease is usually defined as a persistent or recurring disease, affecting a person for three months or longer. The term chronic disease commonly applies to conditions that can be treated but not necessarily cured. The World Health Organisation (WHO) defines chronic diseases as diseases of long duration and generally slow progression.[1]

Health care providers are facing an ageing population due to the general increase in life expectancy, to the progress in quality of life and the improvement of health care delivery. The family physician of the 21st Century will have to deal increasingly more with elderly persons who will understandably have more chronic diseases and more co-morbidities, which will require new skills and different ways of organising health care.[2,3]

According to the WHO, chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading causes of mortality in the world, representing 60% of all deaths.[1] The global prevalence of all the leading chronic diseases is increasing, with the majority occurring in developing countries and projected to increase substantially over the next two decades.[4]

Chronic illness occupies a substantial part of the activity of family physicians in the world.[5,6] The trend of health care development suggests there will be a significant increase in the burden of chronic diseases in the practice of family physicians,[7-9] mostly due to the demographic changes in the more industrialised countries.

Chronic diseases and the health care team

Chronic diseases normally require care by one or more physicians and a health care team. Health professionals can offer different courses of treatment to reduce the effects of symptoms caused by chronic disease, but most chronic illnesses cannot be cured completely. Frequently the result is a lifetime of discomfort, frequent visits to the practice, medical tests, medications, therapies and sometimes surgeries. The cooperation of the patient plays a key role in the

outcome of care. The more the patient understands and learns about the condition, the better the outcome that can be expected.

General practitioners frequently diagnose new cases of chronic morbidity, but are more often involved in the follow-up care of patients. There is an upward trend in this respect, and a substantial number of patients have co-morbidity. This will require patient oriented continuity of care. [7]

There are good reasons, apart from its access to populations, why general practice is well suited to managing chronic disease. Most patients with chronic diseases have more than one chronic condition.[10,11] Primary care practitioners are more effective in dealing with co morbidity than specialist providers. General practice also offers continuity of care, which patients with chronic disease seek as their needs become more complex. [12]

With adequate support from specialist services and a systematic approach, general practice / family medicine can provide good quality of care for patients with most high-prevalence long-term conditions. This has been demonstrated for patients with different chronic conditions. [12] The role of a family physician that cares for patients with several co morbid conditions has also been recognized by patients. [13,14]

Management of chronic diseases

In many countries inadequate financing and lack of manpower to address chronic diseases have been major impediments to chronic disease control. Other impediments are the failure to provide key decision makers with up-to-date evidence on the burden of chronic diseases; a lack of understanding of the economic factors that influence chronic disease risks; and the current orientation of health systems toward acute care. [4]

Some evidence suggests that a minority of primary care patients with chronic illnesses such as asthma, hypertension, diabetes or depression are receiving guideline-level treatments, resulting in less than optimal management of their illness. [15]

Wagner et al [16,17] have described important system barriers to high-quality care of chronic illnesses, including medical care being based on visits of short duration, sole reliance on the physician, limited access to timely expertise of medical specialists and mental health personnel,

inadequate access to key clinical information to help monitor patient progress and adherence, and lack of incentives for chronic illness outcomes. [15]

Persons with co-morbid chronic diseases experience a wide range of barriers to self-care, including several that are specifically related to having multiple medical conditions. Self-management interventions may need to address interactions between chronic conditions as well as providing skills necessary to care for individual diseases. [18] Among the barriers to self-care, are physical limitations, lack of knowledge, financial constraints, logistics of obtaining care, a need for social and emotional support, aggravation of one condition by symptoms of or treatment of another, multiple problems with medications, and overwhelming effects of dominant individual conditions. Many of these barriers are directly related to having co-morbidities. [18]

The willingness of patients to take greater responsibility for their health may be strengthened by policies to give patients a choice of provider and treatments.[19,20] This requires a different organisation of health care, one that moves from the traditional episodic and reactive structure to a more proactive and planned model.

The importance of a new model and an innovative way of organising health teams to deal with persons with chronic diseases and co-morbidities has been often mentioned in the medical literature. [21-28]

The chronic care model

Dealing effectively with persons with chronic diseases requires a new paradigm in designing and organizing health care. A shift in the orientation from a traditional model based on a disease centred approach towards new models of chronic care where the patients' health problems are dealt with in a complementary way by the different professionals from primary to secondary health with community involvement and with the active participation of the patient and his family.[29,30]

This new model should have as its major components: 1) the capacity to mobilise community resources to meet needs of patients - for example, encourage patients to participate in effective community programmes; 2) the ability to create a culture, organisation, and mechanisms that promote safe, high quality care - for example, promote effective improvement strategies aimed at comprehensive change of systems; 3) to empower and prepare patients to manage their health and health care - for example, use effective self management support strategies that include assessment, goal setting, action planning, problem solving, and follow up; 4) to assure the

delivery of effective, efficient clinical care and self management support - for example, define roles and distribute tasks among team members; 5) to promote clinical care that is consistent with scientific evidence and patient preferences - for example, embed evidence based guidelines into daily clinical practice; 6) to organise patient and population data to facilitate efficient and effective care—for example, provide timely reminders for providers and patients. [19,24,31]

An additional feature of a new model of care of chronic diseases is the increased access by patients to accurate health information and the right of patients to participate in the management of their own health information. Accessible information can be of various types such as information on patients' rights, on access to health care services, on prevention, on specific illnesses, on the benefits and risks of participation in clinical research, information on choices between treatments and the risks and benefits of these choices.

Because the person with an illness is a key element in the management of the condition, the chronic care model should be developed in a generalist form, oriented towards primary care, but patient centred. This model is known as the patient-centred clinical method and promotes an approach in which both the disease and the illness experience are explored, trying to understand the whole person, finding common ground regarding problem management, incorporating prevention and health promotion, enhancing the Doctor-Patient relationship while being realistic about the available options. [32]

Asthma is a frequent chronic disease in all ages. Because of its variety of shapes, different levels of severity and age range, frequent problems with patient adherence to treatments, and the importance of self-care, it is one of the chronic illnesses that require better organised care. Considering the need to understand how to better manage asthma and the challenges that it poses, asthma is as a natural field of research and an excellent model of a chronic disease that requires considerable expertise from the health professionals and services.

Doctor-patient relationship and patient enablement

Patient empowerment

The subject of patient empowerment for health is new. In the last decade it has been the focus of numerous research articles, opinion papers, reviews and guidelines from several organisations.

In 2006 the World Health Organisation collected the existing evidence on patient empowerment in a document named "*What is the evidence on effectiveness of empowerment to improve health?*" [33] concluding that "*health promotion should address effective empowerment strategies, such as increasing citizens' skills, control over resources and access to information relevant to public health development; using small group efforts, which enhance critical consciousness on public health issues, to build supportive environments and a deeper sense of community; promoting community action through collective involvement in decision-making and participation in all phases of public health planning, implementation and evaluation, use of lay helpers and leaders, advocacy and leadership training and organisational capacity development; strengthening healthy public policy by organizational and inter-organizational actions, transfer of power and decision-making authority to participants of interventions, and promotion of governmental and institutional accountability and transparency; and being sensitive to the health care needs defined by community members themselves. The study concludes that the most effective empowerment strategies are those that build on and reinforce authentic participation ensuring autonomy in decision-making, sense of community and local bonding, and psychological empowerment of the community members themselves*".

The need for the involvement of a person with a disease in their own care is not only a matter of a passing trend or the simple search for a politically correct statement. It arises from the perception that people with chronic diseases who understand better the nature of their condition, how it develops and its possible complications, that are aware of the risks on inappropriate use or poor adherence to treatment, that are more enabled to deal with their own disease, obtain better results in terms of quality of life, fewer complications and use of less hospital care. [20,34-37]

Patient enablement should not be simply viewed as a matter of improvement of individual control over one's existence. There are good reasons to expect that more enabled patients will lead to a reduction of the workload of health services, allowing free time that can be used to deliver care to less autonomous, less differentiated, or older persons. Among these are persons belonging to ethnic minorities, persons with mental health problems, or those with less economical resources who are usually less able and, therefore, more vulnerable.

Healthier individuals, more able to deal with health promotion, disease prevention, and healthier life styles are also persons that will require less health care in the future. This indicates the importance of including the theme of patient empowerment (or enablement) in the research and

teaching agenda and the promotion of debate within the profession about the ways to encourage it. Doctors and other health professionals could also develop strategies and skills to support the development of patient enablement. [2,38]

Patients with chronic conditions make day-to-day decisions about self-management of illnesses. This reality introduces a new chronic disease paradigm: the patient-professional partnership, involving collaborative care and self-management education. Self-management education complements traditional patient education in supporting patients to have the best possible quality of life with their chronic condition. Whereas traditional patient education offers information and technical skills, self-management education teaches problem-solving skills. A central concept in self-management is self-efficacy–confidence to carry out a behaviour necessary to reach a desired goal. Self-efficacy is enhanced when patients succeed in solving patient-identified problems. Evidence from controlled clinical trials suggests that (1) programs teaching self-management skills are more effective than information-only patient education in improving clinical outcomes; (2) in some circumstances, self-management education improves outcomes and can reduce costs for arthritis and probably for adult asthma patients; and (3) in initial studies, a self-management education program bringing together patients with a variety of chronic conditions may improve outcomes and reduce costs. Self-management education for chronic illness may soon become an integral part of high-quality primary care. [39]

Chamberlain defines empowerment as having a number of qualities, as can be seen in table 1.[40]

Terminology and definition

The term empowerment has its origins in the social sciences and has a considerable range of meanings, interpretations, definitions and disciplines ranging from psychology and philosophy and motivational sciences. Sociological empowerment often addresses members of groups that social discrimination processes have excluded from decision-making processes

Table 1: qualities of empowerment, according to Chamberlain [40]

1. Having decision-making power.
2. Having access to information and resources.
3. Having a range of options from which to make choices (not just yes/no, either/or).
4. Assertiveness.
5. A feeling that the individual can make a difference (being hopeful).
6. Learning to think critically; unlearning the conditioning; seeing things differently; e.g.,
7. Learning to redefine who we are (speaking in our own voice).
8. Learning to redefine what we can do.
9. Learning to redefine our relationships to institutionalized power.
10. Learning about and expressing anger.
11. Not feeling alone; feeling part of a group.
12. Understanding that people have rights.
13. Effecting change in one's life and one's community.
14. Learning skills (e.g., communication) that the individual defines as important.
15. Changing others' perceptions of one's competency and capacity to act.
16. Coming out of the closet.
17. Growth and change that is never ending and self-initiated.
18. Increasing one's positive self-image

The expression patient empowerment has been widely used to describe different states and levels of knowledge, understanding and action in the type of self control over one's illness.

As patients become aware of the lifestyle changes they will have to consent to in order to adjust to their disease, they may experience a distressing feeling of powerlessness. In the field of health-care, empowerment has been acknowledged as an alternative to compliance in order to guide the provider-patient relationship.[41] The empowerment-oriented approach views patients as being responsible for their choices and the consequences of their choices. However, there are many interpretations of the term ''empowerment'', based on different understandings of the concept.

Empowerment is more often defined according to some of its anticipated outcomes rather than to its very nature. However, because they do not respect the principle of self-determination, most anticipated outcomes and most evaluation criteria are not specific to empowerment. Concerning the process of empowerment, analysis shows that (i) the educational objectives of an

empowerment-based approach are not disease-specific, but concern the reinforcement or development of general psychosocial skills instead; (ii) empowering methods of education are necessarily patient-centred and based on experiential learning; and (iii) the provider–patient relationship needs to be continuous and self-involving on both sides. [41]

Empowerment is a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power in people for use in their own lives, their communities, and in their society by acting on issues that they define as important. [40.42]

It is multi-dimensional in that it occurs within sociological, psychological, economic, and other dimensions. Empowerment also occurs at various levels, such as individual, group, and community. Empowerment, by definition, is a social process, since it occurs in relationship to others. Empowerment is a process that is similar to a path or journey, one that develops as we work through it. Other aspects of empowerment may vary according to the specific context and people involved, but these remain constant. In addition, one important implication of this definition of empowerment is that the individual and community are fundamentally connected. [42]

From empowerment to enablement

Recent literature has gradually been using the term enablement, rather than empowerment to describe the result of the doctor-patient or health team-patient interaction resulting in a higher level of control by patients over their own illness. It describes the capability of a person to deal with, understand and control his own disease and refers to the activity of encouraging and capacitating a patient to achieve autonomy.

Enablement is conceptualised as an indicator of the self-efficacy benefits of consulting a doctor, and is expected to be associated with behaviours like treatment adherence and self-care. This is in contrast to satisfaction, which is conceived as a consultation outcome in and of itself. [43-46] So, it is a very similar idea to empowerment, in an individual perspective of an increase in the capacity in relation to health care.

Patient enablement does not simply relate to the management of chronic diseases. It should be seen in a wider sense of individual and collective promotion of independence, autonomy and self-determination of citizens regarding their health. It refers to the capability and right of patients to

control the course of their own medical treatment and participate in the treatment decision-making process without their health care provider trying to influence the decision.

There are several forms of expression of the independence of the citizen in a more or less conscious way: 1) deciding when to see (or not see) a doctor; 2) choosing a physician or other health care provider; 3) Seeking a second opinion; 4) Deciding to accept or to reject a treatment; 5) Using complementary or alternative medicines before, after or during medical treatment; 6) Using self-medication or over the counter (OTC) medication; 7) To interrupt a treatment.

Enablement refers also to the capacity of a patient to accept or disagree with a physician's treatment decision. The terms compliance or adherence have been used to describe the degree to which a patient correctly follows medical advice on treatment, prevention or changing in life-style. In a patient-centred model of care, these concepts are gradually being replaced by the term concordance.

From compliance to concordance

According to the definition of the Royal Pharmaceutical Society of Great Britain, concordance is a new approach to the prescribing and taking of medicines. It is an agreement between a patient and a health care professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which the health care professionals recognize the primacy of the patient's decisions about taking the recommended medications. [47]

While compliance refers to something that patients do or do not do with their medicines, concordance refers to a relationship between two or more parties. A patient can be non-compliant but an individual cannot be non-concordant. Only a consultation, or a discussion, can be non-concordant. Concordance also differs from compliance in acknowledging and valuing the patient's perspective. The two terms are related however, as concordance may well lead to improved prescribing and medicine-taking. Indeed the precise relationship between concordance and compliance (or adherence) needs to be carefully researched. What is already clear is that non-concordance can lead to non-adherence. [48]

The introduction of the concept of concordance can promote a change in the attitudes of health professionals moving away from the model of compliance in which patients were only expected to

do as they were told. It is an approach which combines two previous strands in the compliance literature: doctor–patient communication and patients' health beliefs.

The expected professional change towards a more extensive use of a patient centred model of care with a wider focus on patient enablement and the practice of concordance in the doctor-patient relationship can lead to better care of patients with chronic diseases, including persons with asthma.

The management of asthma in family medicine

Definition of asthma

Asthma is defined by the Global Initiative for Asthma (GINA) project as a chronic, inflammatory disorder of the airways in which many cells and cellular elements play a role. The chronic inflammation is associated with airway hyperresponsiveness that leads to recurrent episodes of wheezing, breathlessness, chest tightness, and coughing, particularly at night or in the early morning. These episodes are usually associated with widespread, but variable airflow obstruction within the lung that is often reversible either spontaneously or with treatment.[49]

Defining asthma for research purposes and to apply the definition to epidemiological studies poses a further challenge. Currently there is disagreement on the exact pathophysiology of asthma and, therefore, it is unclear how asthma should be exactly defined in studies. In epidemiology, the most common solution has been to adopt questionnaires and dichotomous operational definitions of asthma developed for large cross-sectional prevalence studies. Choosing a cut-off point for a dichotomous definition of disease is a difficult trade-off between sensitivity and specificity. The best cut-off point depends largely on the aims of the study.[50]

Clinical diseases, e.g. asthma, are usually treated as dichotomies in epidemiological research. However, most, if not all, chronic diseases are not true dichotomies. Among asthmatics, continuous symptom scores have been used to measure asthma severity and asthma-related quality of life. However, the possibility of combining different symptoms or using a continuous asthma score to define asthma has been less explored.[50]

Asthma diagnosis

Asthma diagnosis presents a challenge to the physician. Asthma has many features and is present in different levels of severity. In the same subject it has a considerable lifelong or even daily variability. Facing possible asthma symptoms, clinicians should follow a diagnostic path starting with a careful collection of a clinical history. In most subjects, the clinical expression is sufficient for a strong probability of diagnosis, but, respiratory function tests should be preformed as soon as possible, whenever they are available.

Asthma should be suspected in patients with recurrent respiratory symptoms, particularly cough, wheeze, chest tightness and dyspnoea. Alternative diagnoses should be excluded. An objective lung function test such as spirometry can be used to confirm airway obstruction and to demonstrate reversibility of obstruction with bronchodilator medication.[51]

The consensus from different guidelines [49,52-54] suggests that the following clinical features are related to the probability of asthma in those with episodic symptoms:

- More than one of the following symptoms – wheeze, cough, difficulty breathing, chest tightness – particularly if these are: frequent and recurrent; worse at night and in the early morning; occur in response to, or are worse after, exercise or other triggers, such as exposure to pets; cold or damp air, or with emotions or laughter; or occur apart from colds.
- Personal history of atopic disorder
- Family history of atopic disorder and / or asthma
- Widespread wheeze heard on auscultation
- History of improvement in symptoms or lung function in response to adequate therapy

Asthma as a chronic disease

Asthma, as defined by the WHO, is a chronic disease characterized by recurrent attacks of breathlessness and wheezing, which vary in severity and frequency from person to person. Symptoms may occur several times in a day or week in affected individuals, and for some people become worse during physical activity or at night.[55]

In asthma, there is a wide variability of presenting features in different patients and in the same patient in different stages of the disease or according to external conditions. The unpredictability

of the recurrence of symptoms, with some long symptom free periods followed by very incapacitating attacks present a special challenge for health professionals in order to provide adequate services that are simultaneously established and flexible to accommodate less concordant patients.

Asthma control and follow-up

As many other chronic diseases, asthma requires frequent office visits for follow-up. Deciding how often patients should visit has to be tailored to the level of severity and control, individual characteristics of the patient (personality, education, enablement), exacerbations in the recent past and the existence of a health care team.

Encouraging regular review may be difficult, mostly in cases of intermittent or mild persistent asthma, in the absence of exacerbations, where patients fail to see the usefulness of seeing a doctor.

As for many other chronic conditions, the ritual of routine visits usually includes monitoring to check on the progress or regression of the disease and the development of complications. Such checks require that we choose what to monitor, when to monitor, and how to adjust treatment.[56]

The core of a routine review is the opportunity to identify patients with sub-optimal control and (for both patients and professionals) the need to adopt an approach of 'zero tolerance' to symptoms. Recognition of the inter-relationship of professional reviews and patient self-management underpins the partnership as future management strategies are negotiated.[57]

Monitoring is periodic measurement that guides the management of a chronic or recurrent condition. It can be done by clinicians, patients, or both.[56]

In the GINA 2009 workshop report, the Component 3 deals with assessment, treatment and monitoring of asthma.[49] The report recommends that, when asthma control has been achieved, ongoing monitoring should be maintained at regular intervals. No clear periodicity is defined, though intervals of 3 or 4 months are mentioned as the interval needed to observe the full benefit of most classes of control medications.[49]

Although monitoring is common in clinical practice, the principles of monitoring have not been well conceptualised, which in turn has led to suboptimal care. Chronic care could potentially be improved (and often at reduced costs) if for each chronic disease we determined whether and

how monitoring was necessary, set explicit monitoring ranges and provided appropriate graphical representations that aided decision making, recognised the need for different optimal intervals for different phases, and understood better when and how to adjust treatment to avoid the increases in variability caused by over adjustment.[56]

Levels of control

Studies have shown that the use of healthcare resources, the level of lifestyle impairment, and quality of life, are all closely linked to the level of asthma control. With better control, there is less impairment, lower use of healthcare resources, and higher quality of life.[58-60]

An Official joint Statement from the American Thoracic Society and the European Respiratory Society contributes to the definition of asthma severity and control. Asthma severity is defined as the difficulty in controlling asthma with treatment after exclusion of modifiable factors such as poor adherence, smoking, and co-morbidities. Severity largely reflects the required level of treatment and the activity of the underlying disease state during treatment.[61]

Asthma control encompasses not only the patient's recent clinical state (symptoms, night waking, reliever use, and lung function), but also considers their ''future risk'' – that is, their potential for experiencing adverse outcomes, such as loss of control in the near or distant future, exacerbations, accelerated decline in lung function, or treatment-related side effects. It is emphasised that even if current poor control predicts future poor control and health care utilisation, other pathologic and physiologic measures, independent of the level of current clinical control, also influence future risk.[61]

The initial Global Initiative for Asthma (GINA) treatment guideline published in 1993 and subsequent reports was based on disease severity grading as intermittent, mild persistent, moderate persistent and severe persistent asthma. Classification of asthma by severity is useful when decisions are being made about management at the initial assessment of a patient. It is important to recognize, however, that asthma severity involves both the severity of the underlying disease and its responsiveness to treatment.

Because of these considerations, the classification of asthma severity is no longer recommended as the basis for ongoing treatment decisions. In the GINA report of 2007, and subsequent updates, a new approach was accepted and treatment recommendations are based on the level

of asthma control rather than disease severity.[62] The new approach classifies asthma in three levels of control: controlled, partly controlled and uncontrolled.

Assessing asthma control

Assessing asthma control in the physician's office requires a combination of validated symptom-based tests and the measurement of respiratory function such as Peak Expiratory Flow (PEF) and / or the Forced Expiratory Volume in 1 second (FEV1).

Asthma control can be adequately measured using the *Asthma Control Questionnaire* (ACQ)[63-65] or the *Asthma Control Test* (ACT).[66,67] These questionnaires provide the patient and the physician with more objective measures of the level of control of the disease and the need to adjust treatment. They are short, well-validated questionnaires commonly used in research and in clinical practice. The Asthma Control Questionnaire uses five morbidity questions plus an optional measure of the forced expiratory volume in one second (FEV1). It has been tested for use in clinical practice. The Asthma Control Test uses similar morbidity questions but also includes a rating of overall control which includes the patient's perspective, with a score of 20 or more indicating good control.

Recently a new promising tool has been developed in Portugal, the Control of Allergic Rhinitis and Asthma Test (CARAT). It is a brief self-administered questionnaire used to quantify the degree of control of allergic rhinitis and asthma in adult patients. It is a reliable and valid instrument for assessing control of asthma and rhinitis in individuals in clinical practice and for comparison of groups of patients in research.[68,69]

In a discussion paper, Pinnock et al suggest that asthma reviews in primary care should incorporate three key steps: [57]

1. Assessing control in order to target care appropriately
2. Responding to that assessment by identifying reasons for poor control and adjusting the management strategy accordingly
3. Exploring patients' ideas, concerns and expectations, and guiding self-management to facilitate on-going control

Self-management and control

Self-management is a regular proposal of most integrated national asthma plans.[49,52,63,70] The creators of such programmes have based their suggestions to incorporate this item in the existing literature, though there is contradicting evidence about its usefulness.[20, 71]

Some authors conclude that self management of asthma prevents exacerbations, improves care, and is a cost effective investment. Patient education is crucial and should be given in a structured way. Patients should be taught to understand their symptoms and to monitor peak expiratory flow at home. Patients should know how to act when signs of asthma deterioration first appear. There should always be supervision and continuity in asthma care.[35] Self-management lowers the burden of illness as perceived by patients with asthma and is at least as effective as the treatment usually provided in primary care. Self-management is a safe basis for intermittent treatment with inhaled corticosteroids.[72]

Although a clinician may initiate education, it is the responsibility of all members of the team to provide the on-going, consistent support for guided self-management.[57]

In spite of contradictory evidence and some difficulties in reaching patient concordance due to some variation in professional skills, adequate management and patient's willingness to be involved, guided self-management of asthma might promote better care and quality of life in asthmatic patients.

The contribution of family practice to the care of patients with asthma

National asthma programmes or guidelines recommend a high level of community involvement in asthma care for family physicians and community nurses. Most asthmatic patients are already routinely seen by family physicians. It is a frequent problem in the community, so care should mostly be organised at community level. Family physicians and community nurses should be adequately trained in asthma diagnosis, management, follow-up and referral. Other community health care professionals can and should be involved in the care of patients with asthma.

Routine consultations should include a regular assessment of asthma control, reviewing the diagnosis, checking and correcting inhaler technique, assessing adherence, asking about, and treating rhinitis, adjusting therapy according to evidence-based guidelines, exploring perceptions

and supporting self-management and ensuring easy and fast access to professional advice between scheduled appointments.[57]

The burden of asthma

According to the WHO GARD programme estimates, hundreds of millions of people of all ages suffer from chronic respiratory diseases which include asthma and respiratory allergies, chronic obstructive pulmonary disease, occupational lung diseases and pulmonary hypertension. More than 500 million patients live in developing countries or in deprived populations. Chronic respiratory diseases account for four million deaths annually. Measured in disability-adjusted life years (DALYs), in 2005 the burden of chronic respiratory diseases was projected to account for 4% of the global burden and 8.3% of the burden of chronic diseases. It is estimated that 300 million people of all ages worldwide have asthma and the prevalence has increased following changes to a modern, urban lifestyle. Globally, 250 000 people die of asthma every year, deaths being related to lack of proper treatment. Treatment for asthma is not available to all people who have asthma.[73-75]

The burden of asthma assessed by disability-adjusted life years (DALYs), which ranks 22 worldwide, is similar to that of other chronic diseases such as diabetes or Alzheimer disease. The costs of asthma are high in severe or uncontrolled asthma. Many children with undiagnosed asthma miss school and require emergency department visits. [73]

Asthma prevalence

There are many published studies on the prevalence of asthma but the absence of a specific and commonly accepted definition of asthma makes reliable comparison of reported prevalence from different parts of the world problematic.

In the World Health Survey from 2003,[76] the prevalence of diagnosed asthma showed a narrow range across countries. There was a 10-fold variation in current wheezing symptom prevalence across countries ranging from 2.4% in Vietnam to 24.3% in Brazil. The majority of estimates fell within a fourfold range of prevalence, with Vietnam the lowest at 1.8% and Australia the highest at 32.8%.

The 2003 Global Burden of Asthma document published on behalf of the GINA project compares the mean prevalence of clinical asthma in different regions.[75] It ranges from 2.1% in Central North

Asia (China/Taiwan/Mongolia) to 16.1% in the United Kingdom and Republic of Ireland. Prevalences are higher in North America, Oceania and West and Eastern Europe than in Asia or Africa. Southern Africa (8.1%) and South America (9.9%) have intermediate prevalences.

The prevalence given for Western Europe (including Portugal) is 5.9%. These studies have gathered data from different sources and present a rather different range of values.

Some of the most recent publications suggest that asthma prevalence ranges from 7.2% to 12.2%. In the U.S. National Surveillance for Asthma study published in 2007 the overall prevalence of asthma was 7.2%.[77] In the discussion section of the study "*Asthma in an Urban Population in Portugal: A prevalence study*", more data is given from prevalence surveys in different countries and regions.

Asthma incidence

Asthma is a common chronic disease in childhood with a high prevalence in other age groups as well; however there is wide variation in the prevalence and incidence of the condition between and within countries. [78-83]

Asthma incidence studies are rare as the estimation of the incidence of asthma presents some methodological problems.[84] The European Community Respiratory Health Survey (ECRHS) calculated the incidence of asthma from the reported age of the first attack of asthma and observed a wide variation; the incidence rate of childhood asthma (0–15 years) was found to vary from 1.3 to 6.7 per 1,000 person-years. The corresponding variation in the incidence of adult onset asthma was from 0.3 to 2.9. [81] Eagan et al recalculated a pooled estimate of the incidence of adult asthma of 4.6 per 1,000 person-years in women and 3.6 per 1,000 person-years in men. [83]

Surveys from other countries report different results, such as the rate of 0.95 reported among older adults in the US, [85] 1.6 among adults in Finland,[86] or 1.08 among adults in Sweden, [87] and 5.53 reported among adults in Spain. [88]

Asthma workload in family practice

Asthma is a frequent health problem in the community and family doctors are especially involved it its diagnosis, control and follow-up. This accounts for the importance of asthma in primary health care.

In a three year survey within the Portuguese Sentinel Practice Network,[1] participants studied consultations related with asthma and the workload generated. A report of this data was produced for the Network and the original data was presented in the WONCA Europe Regional Conference in Amsterdam in 2004. [89] The study design was a cross-sectional study of asthma related consultations with patients from the family physicians' (FP) lists from the Portuguese Sentinel Network in 2000-02. 5,997 asthma related consultations were reported. There were 18.2 consultations for each 1,000 registered patients. 58.3 % were female patients. There was some variability on the number of cases per participating FP. In 66.1% of the consultations there was a prescription renewal, in 26.4% a follow-up, in 19.6% an acute episode was reported and in 7% there was a new case of asthma. The top therapeutic groups prescribed were inhaled beta-2 agonists and steroids.

The scientific literature is not rich on recent data about the impact of asthma in the family physicians' workload. Some studies may help to exemplify the burden of asthma in family medicine. In a survey from the UK, Osman et al report 38.7 consultations per 1000 person years at risk with a considerable age variation. [90]

A Swiss study by Bollag et al, shows that the overall consultation rates for asthma per 1000 primary care consultations increased from 1989 to 1994 then stabilized and have declined since 2000. These figures represent the burden of consultations for acute asthma on the total number of consultations in the sample.[91]

A study from the UK by Fleming et al reports data from 1989 to 1998 and concludes that new episodes of asthma reported to general practitioners increased between 1989 and 1993, and have since declined. For every 10 persons (all ages) reported with asthma there were seven new episodes and 22 consultations. [92]

[1] This survey used data from the first three years of the study *Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network.*

Aims and objectives

The aims of the thesis are:

1. To assess the epidemiological burden of asthma in the community in order to understand its impact on health services and on the practices of family physicians.
2. To describe the variety of shapes, the age range, and the different levels of severity of asthma to be able to offer patients better treatment options, a higher level of control of the disease and better quality of life.
3. To understand the relationship between patients' enablement and the level of control of asthma and the quality of life to be able to develop adequate clinical strategies to deal with the disease.
4. To confirm the feasibility of using questionnaires and clinical tools to measure asthma control and patient enablement and wellness in the context of the family practice consultation.

These general aims lead to some more **specific objectives**:

1. To assess the quality of the diagnosis of previously reported new cases of asthma in patients of family physicians belonging to the Portuguese Sentinel Network in 2000-2002 using a questionnaire on diagnostic criteria.
2. To estimate the incidence of asthma in Portugal over a four year period (2000-02).
3. To contribute to the validation of data of the Sentinel Network.
4. To determine the prevalence of asthma by gender and stratified age groups in the Horizonte Family Health Unit in Matosinhos Portugal in 2009.
5. To assess the severity of asthma, the use of medication and quality of life in a population of asthmatics.
6. To study the factors that influence the level of enablement of patients with asthma.
7. To study the effect of enablement on the quality of life and level of disease control in a population of asthmatics.
8. To estimate the different degrees of enablement and their impact on morbidity.
9. To plan future research on asthma that constructs a continuing research line in clinical and academic family medicine.

Methods

Methods

The complementary nature of the three studies in this thesis

The methods used in the three studies included in the current thesis are described in the published reports of these studies. The methods used are different, though complementary. Together, they allow an overview of the central features of asthma in society, from the description of its incidence and prevalence to the outcomes of individual care in a family practice setting.

The study, "*Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network*" was developed within the framework of the Portuguese Sentinel Practice Network (PSPN). The study used a convenience sample of physicians and patients from a research network. A doctor-based diagnosis was made with no patient input, as the study used routine data collected by family physicians in clinical encounters. The researchers observed, described and analysed data but did not have full control over its quality.

This study was an original approach to the routine collection of data by the PSPN. The Sentinel Network is an important epidemiological tool that allows the surveillance of health problems for which other sources of data are missing or deficient. However it has some limitations. The quality of the routine data collected by the PSPN has been discussed in the literature.[93] It is important to understand these limitations to be able to develop research that goes beyond the routine collection of data.

The Network uses a weekly report sent by mail or inserted in an internet-based form to conduct its studies. Each participating physician records the events of interest that occur in their registered patients. The PSPN coordinating team collects information about the patient list of each participant, calculating the workload of each physician and estimating the incidence of the conditions studied.

A study on asthma in family medicine was done in the PSPN. After the routine collection of data was concluded and reports of the first phase had been produced for the Network, the authors concluded that the number of reported rates and incidence estimates of asthma had a large variability among participating physicians. During the discussion at the network general meeting, it was apparent that variation in diagnostic criteria had an influence on these results. Doubts

were raised regarding the ability of the Network to study asthma incidence through routine data collection.

As a result, a satellite study was proposed. Each of the physicians that had participated in the routine data collection on asthma was later-on asked to report on the diagnostic features for all the newly diagnosed cases of asthma, as described in the published survey.

A new questionnaire was developed for this purpose and data was gathered through the usual Network method. Each participating physician accepted to review their data and the diagnostic criteria used. This critical evaluation resulted in more accurate information on the diagnostic criteria.

This is an approach that could easily be replicated to the study of other chronic diseases. Sentinel networks routinely collect and process a large amount of data but a deeper and more structured observation is needed in order to achieve a higher accuracy**.**

The study, "*Asthma in an Urban Population in Portugal: A prevalence study*", was designed to calculate the prevalence of asthma using a different and innovative approach. The motivation for this survey was the poor quality of the available information about asthma prevalence in Portugal. In previous surveys carried out in Portugal, before 2006, studies included limited age groups or used methodologies which provided questionable estimates of the prevalence rates.

A combination of a medically verified asthma diagnosis using medical records and the use of self-reported symptoms with the ISAAC questionnaire helped to gather the best available knowledge about asthma from both patients and physicians.

The researchers studied a practice population using a random sample of registered patients with replacement of non-responders. Data were collected using two questionnaires: a physician questionnaire and a patient questionnaire. The diagnostic procedures were based on a combination of the answers given by the patient on respiratory symptoms and the physician's knowledge of the patient's asthma status. It was possible to control data quality and to include clinical information obtained from both patients and doctors. Stricter diagnostic criteria were applied, resulting in a combination of data from different sources that allowed a more precise diagnosis.

Unlike many other surveys that have relied on either the physicians' information or on the patients' knowledge about the disease, this study obtained the best possible data from both sources.

The study "*Enablement and quality of life in asthma patients (the EQLAP study): a cross-sectional study from a family practice*", aimed at assessing the severity of asthma, medication use, asthma control, the level of patient enablement and the quality of life in a population of asthmatic patients treated in primary care, and to study the relationship between enablement and the quality of life of asthma patients.

The study used a random sample of patients extracted from a data base of patients with known asthma. Clinical information on patient behaviour, attitudes, and measures of quality of life were obtained. Each patient was individually interviewed and objective measures of respiratory function and disease control were gathered. This study represents a transition from a research stance that seeks to measure diagnoses and disease control, to one that seeks to understand the point of view of patients and to study their attitudes and behaviour. The former approach has been used in many published studies. The new approach in an area of study where research tools are not yet fully developed requires special attention to study design and validation and calibration of study questionnaires and an understanding of models of relationship and causation. These are two different and complementary approaches which can enhance our understanding of asthma.

These studies complement each other by evolving from population epidemiology, through clinical assessment into patient centred measures of well being and enablement. They connect broad knowledge from epidemiological data to clinical practice and the individual patient. The connecting line is the understanding of how the knowledge about the burden of disease in the general population helps doctors in clinical practice. This information can be combined with patient-centred clinical measures to empower the family physician with additional tools to obtain better control of asthma and improve the quality of life of patients.

Results

Results

Overview of the studies completed by the candidate

This section is an overview of the results of the three studies that comprise this thesis. The description of the results of the third paper is longer than the version submitted for publication to present additional material relevant to the understanding of patient empowerment, asthma control and quality of life.

The first survey, *Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network* aimed to assess how physicians in a Portuguese sentinel practice network perform using standardised diagnostic criteria. It studied patients consulting with the network physicians with complaints suggestive of asthma over a four-year period. Symptom frequency and diagnoses of asthma were tabulated and diagnostic accuracy was computed by dividing the rate of asthma diagnosis by the true rate using established diagnostic criteria.

Asthma incidence in Portugal was calculated and the value obtained was close to published rates if accepted criteria are used.

The second study had the title: *Asthma in an Urban Population in Portugal: A prevalence study.*

Its aim was to estimate the true prevalence of asthma by gender and age groups in the population of the area covered by one urban Health Centre in Portugal and to estimate the national prevalence of asthma. An observational study was conducted in 2009. A random sample of patients, stratified by age and gender was obtained from the practice database of registered patients. Data were collected using a patient questionnaire on respiratory symptoms and the physician's best knowledge of the patient's asthma status. The prevalence of asthma was calculated by age and gender.

The prevalence of asthma found in the present study was higher than that found in some studies, though lower than that found in other studies.

The third study was called *Enablement and quality of life in asthma patients (the EQLAP study): a cross-sectional study from a family practice*

The study was a cross-sectional study conducted in an urban population in northern Portugal. Data were collected both from clinical records and questionnaires administered to a stratified

random sample of asthma patients treated in this clinic. The modified Patient Enablement Instrument (mPEI) was used to assess enablement and the Asthma Quality of Life Questionnaire (Mini-AQLQ) was used to assess quality of life. Asthma control was assessed using the Asthma Control Test (ACT). Pulmonary function was assessed by measuring peak expiratory flow (PEF) and forced expiratory volume at one second (FEV1).

Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network

Corrigendum

Error in Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network by Correia de Sousa et al. Primary Care Respiratory Journal (2010); 19(4): 352-357.

The abstract, the results section and the conclusions section correctly state that the diagnostic accuracy of the physicians in this study was 84%.

The erroneous figure of 62% appears in the first paragraph of the discussion section on page 354 and again at the bottom of page 356 when referring to diagnostic accuracy.

Primary Care Respiratory Journal (2010); **19**(4): 352-357

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ORIGINAL RESEARCH

Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network

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Abstract

Aims: Asthma is frequently under-diagnosed with a wide variation in incidence rates. We aimed to assess how physicians in a Portuguese sentinel practice network perform using standardised diagnostic criteria.

Method: Patients consulting one of the 43 network physicians with complaints suggestive of asthma were enrolled in the study over a four-year period. Symptom frequency and diagnoses of asthma were tabulated. Diagnostic accuracy was computed by dividing the rate of asthma diagnosis by the true rate using established diagnostic criteria.

Results: Over four years, 43 physicians followed 32,103 patients (128,412 patient-years) and diagnosed asthma in 310. The diagnosis was confirmed in 260 cases, giving a true incidence rate of 2.02/1000/year (95% confidence interval 1.8 to 2.2) and an accuracy of diagnosis of 84%.

Conclusions: Asthma incidence approaches published rates if accepted criteria are used. Educational efforts to ensure more accurate diagnosis may improve outcomes for asthma patients.

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Keywords asthma, incidence, diagnosis, diagnostic accuracy, family practice, general practice, Portugal

Introduction

Asthma is the most common chronic disease in childhood worldwide with a high prevalence in other age groups as well, yet there is wide variation in the prevalence and incidence of the condition between and within countries.[1-5] Making the diagnosis of asthma is necessary to ensure correct treatment and improvement in quality of life. Accepted diagnostic criteria for asthma are available but are not widely applied.[6]

One way of standardising the diagnostic process is by the use of research criteria or research protocols by groups of physicians. This is the method used in sentinel research networks in which participating doctors agree on diagnostic criteria for one or more conditions to allow for surveillance or study of these conditions in normal practice. The Portuguese Sentinel Practice Network (PSPN) is one such research network. It has been in existence since 1980 and currently has 145 members.[7] It is a Health Observation System consisting of family physicians. The objectives of the network are to estimate incidence rates for diseases or conditions occurring in the sentinel physicians' patient lists, to participate in the epidemiological surveillance of diseases occurring in the community, to identify potential outbreaks, and to build a database that allows the epidemiological analysis of diseases with public health interest.

Following the Global Initiative for Asthma (GINA) workshop in 1995,[8] there was an increased awareness in Portugal of the need for better knowledge of the burden of asthma. Multidisciplinary GINA groups were formed in order to disseminate the guidelines and to develop educational activities on asthma diagnosis and control. There were no readily available data on the incidence of asthma in Portugal, and the Portuguese National Plan for Asthma Control[9] had not yet been published. The plan included an appeal for an ongoing epidemiological survey of asthma.

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In 1999 the PSPN decided to study the incidence of new cases of asthma presented to members of the network over a four-year period. This paper presents data from this network study and explores the question of diagnostic accuracy of asthma by network members. We wished to determine the incidence of asthma in this population and, in particular, to validate the diagnosis of asthma made by general practitioners (GPs) using accepted diagnostic criteria as a standard.

Methods

In 1999 the Portuguese Sentinel Practice Network agreed to conduct a study on the incidence of asthma in network practices. Participation in the network is voluntary and there are two types of co-operation: weekly notification of new cases from the participating practices; or participation in national and international studies proposed by the participants. Data is collected during routine consultations. Network members report findings via the Internet or by using regular mail to a co-ordinating team located at the Portuguese National Institute of Health (INSA). The Portuguese Association of Family Physicians is also a partner in the project.

Comparison of the study population with the Portuguese population during the study period

The composition of the study population followed by the PSPN was compared to the composition of the Portuguese population in 2003 using national census data[10] and was found to be similar. Young patients aged 0 to 14 years are slightly over-represented in the research network population constituting 15.4% of the network population compared to 14.8% in the general population. Patients over 65 years of age were also over-represented – 18.4% compared to 16% in the general population. Patients in the 15-65 year age group were underrepresented in the study population (66%) compared to the general population (67%). As a result, incidence rates were standardised by age to the Portuguese population in 2003.

Data collected by the reporting physicians during the first network study on asthma (2000-2003) were collated and validated in 2004. A first report was produced in 2005. Because a wide variety of rates of new cases of asthma were reported by study participants, the authors decided to conduct a second study in order to assess the diagnostic accuracy of new cases of asthma and to validate the incidence rate.

During the study period, the population of the sentinel practices remained relatively stable with an increase of 13 patients per practice per year or less than 1% of the average practice size of 1596 patient per doctor (personal communication, Isabel Falcão, Portuguese Sentinel Practice Network).

In 2005, all physicians reporting at least one new case of asthma during the study period were asked to participate in this study. Data were collected retrospectively from all participants. Physicians were asked to report demographic data on each patient including age and gender. Diagnostic criteria for the diagnosis of new cases of asthma were collected. These included items in the history including cough and night-time wheezing, items in the physical examination such as expiratory wheezing, and items from additional examination such as peak expiratory flow (PEF) measurement, spirometry and skin testing. In addition, data from referrals to hospital specialists and the type of specialist were recorded along with the place of diagnosis of asthma.

The criteria used for the diagnosis of asthma in this study were the GINA criteria published in 2005.[8] A definite diagnosis of asthma was made in the presence of at least one positive item from the medical history, one from physical examination and one from additional tests (see sections 1, 2 and 3 in Table 2). A probable diagnosis of asthma was made if one item was present in only two out of three categories.

The incidence rate per thousand persons was calculated by dividing the number of definite or probable cases of asthma reported by the total number of patients in the population under observation during the four year study period x 1000. The annual incidence was computed by dividing this rate by 4 and was standardised by age and sex for the Portuguese population in 2003. Comparisons of incidence rates by gender were made using the Student t-test with significance set at the $p<0.05$ level.

Results

Over a four-year period, 43 physicians participating in the study followed an average of 32,103 patients per year, representing 128,412 patient years of observation. This represents 0.3% of the 10,569,592 inhabitants living in Portugal in 2005.[11] During the study period, 310 new cases of asthma were reported. The 260 cases reported by the 43 network physicians represent a mean of 5.66 new asthma cases (95% CI 3.95 to 7.37) reported by each physician with a range of 1 to 26 cases reported per physician.

Table 1. Characteristics of the newly diagnosed asthmatic patients (n=310).

Mean age	34.1 years, 95% CI [31.51-36.71], sd 23.29
Males	29.08 years, 95% CI [24.92–33.25], sd 24.11
Females	37.79 years, 95% CI [35.54-41.04], sd 22.02
Median age	33 years
Age range	0 to 85 years

T-test for difference in mean age between genders: t= 3.30; p= 0.001; mean difference 8.7 years; 95% CI [3.52-13.89]

The characteristics of the newly-diagnosed asthmatic patients are presented in Table 1. The mean age of the patients was 34.11 years (95% CI 31.51 to 36.71 years, s.d. 23.29 years, range 0 to 85 years) and 57.7% of the patients were female. The mean age of newly-diagnosed male asthmatics was significantly lower than the mean age of newly-diagnosed females (29 years vs. 38 years, p<0.01).

The diagnostic criteria used to make the diagnosis are listed in Table 2 which presents the frequency of symptoms, physical signs and laboratory findings encountered. Recurrent wheezing was the most common symptom recorded. The place of diagnosis and the specialty of the diagnosing physician are also given in Table 2. The primary care setting was the most common setting for diagnosis (in 60% of cases) with the diagnosis being made by a family physician (GP) in 56.8% of cases. The diagnosis of asthma was positive or probable in 260 new cases of asthma reported. This included 110 males and 150 females.

Table 2. Diagnostic criteria for asthma used in this study.

	Number (%) positive
Wheezing High-pitched expiratory whistling sounds– especially in children.	179 (59.7%)
History of one of any of the following:	
Cough (worse particularly at night)	184 (59.4%)
Recurrent Wheeze	216 (69.7%)
Recurrent difficulty in breathing	208 (67.1%)
Recurrent chest tightness	69 (22.3%)
Demonstration of reversibility of airflow obstruction with a short-acting bronchodilator by:	
Clinical observation	214 (69%)
Peak expiratory flow	58 (18.7%)
Spirometry	68 (21.9%)
Who made the diagnosis?	
Family Physician	176 (56.8%)
Pediatrician	28 (9%)
Pneumologist	25 (8.1%)
Allergologist	24 (7.7%)
Other	19 (6.1%)

The corrected asthma incidence rate for all ages was found to be 2.02 cases per 1,000 persons per year (95% CI, 1.8 to 2.2). For males the incidence was 1.8/1,000 persons/year (95% CI, 1.5 to 2.1) and for females 2.23/1,000 /year (95% CI, 1.8 to 2.6).The difference in incidence by gender was statistically significant (p=0.01).

The incidence of asthma by age varied from a maximum of 5.93 in the age group 0 – 4 years to a minimum of 0.93 in those over 75 years (Table 3). Asthma incidence was higher in males in the younger age groups and higher in females in the older ages.

The proportion of patients meeting the diagnostic criteria for asthma is given in Table 4. All diagnostic criteria for asthma were present in 50% of the cases diagnosed. Most criteria were present in 29.7%. The diagnosis was confirmed by a hospital consultant in an additional 4.2% of cases. Therefore, asthma diagnosis was positive or probable in 83.9% of cases.

Discussion

This study found that the annual incidence of asthma in the general population in Portugal was 2.02 cases/1000 using data collected from a large sentinel practice network. It also found that the accuracy of the diagnosis by family physicians/GPs was 62% using accepted diagnostic criteria. We believe this is the first report of this nature from Portugal.

Asthma incidence studies are infrequent, since the estimation of asthma incidence presents some methodological problems.[12] The European Community Respiratory Health Survey (ECRHS) calculated the incidence of asthma from the reported

Table 3. Asthma incidence (new cases per 1000 persons) by age, 2000-2003.

Age group	Males	Incidence	Females	Incidence	M + F	Incidence
00-04	25	7.58	13	4.18	38	5.93
05-09	10	3.11	9	2.71	19	2.91
10-14	11	3.21	6	1.77	17	2.49
15-24	14	1.66	20	2.33	34	2.00
25-34	7	0.69	23	2.22	30	1.47
35-44	15	1.64	27	2.73	42	2.21
45-54	10	1.29	14	1.72	24	1.51
55-64	7	1.13	19	2.62	26	1.94
65-74	8	1.37	13	1.78	21	1.60
75 +	3	0.80	6	1.01	9	0.93
TOTAL	110	1.80	150	2.23	260	2.02

Table 4. Proportion of patients meeting diagnostic criteria for asthma.

	n	%
All criteria present	155	50.0
Most criteria present	92	29.7
Diagnosis confirmed by hospital consultant	13	4.2
Diagnosis not confirmed	50	16.1
Total	310	100.0

Table 5. Asthma incidence standardised by age and sex to Portuguese population of 2003.

Age group	Males standardised incidence rate/ 1000/year	Females standardised incidence rate/ 1000/year
0 to 14 years	4.6	2.8
15 to 64 years	1.2	2.3
65 and over	1.2	1.5

age of the first asthma attack and observed a wide variation; the incidence rate of childhood asthma (0–15 years) varied from 1.3 to 6.7 per 1,000 person-years. The corresponding variation in the incidence of adult onset asthma was from 0.3 to 2.9.[13] Eagan *et al*. recalculated a pooled estimate of the incidence of adult asthma of 4.6 per 1,000 person-years in women and 3.6 per 1,000 person-years in men.[5]

Internal validity

Portuguese family physicians have relatively stable patient lists. The age-gender distribution of the lists is updated yearly and reported to the Portuguese Sentinel Practice Network (PSPN) coordination centre. The PSPN uses the participating physicians' lists as a denominator for estimating incidence rates. Whenever participating doctors are absent for prolonged periods from their practices, their lists are removed from the denominator for statistical purposes. During the study period there was a mean change in list size of less than 1% per year per practice.

Questionnaire / diagnostic criteria

The diagnostic criteria for asthma used in this study were the criteria listed in the 2005 GINA guidelines. They have been adapted further for use in primary care by the IPCRG in 2006[14] and further updated by GINA in 2008.[15] Future study of asthma incidence should use the latest diagnostic criteria.

Comparison of findings with other published studies

This study found an annual incidence of asthma of 2.02 cases per 1000 population per year. This is higher than the rate of 0.95 reported among older adults in the US,[16] 1.6 among adults in Finland,[17] or 1.08 among adults in Sweden.[18] However, it is less than the rate of 5.53 reported among adults in Spain.[19] The figures in this study are similar to findings among adult patients in two studies conducted in the USA.[20,21]

Table 6. Comparison of asthma incidence rate (new cases per 1000 people) between the PSPN study and the study by McWhorter *et al.*[21]

Age group (years)	PSPN, 2004	McWhorter, 1988[21]
25-34	1.5	1
35-44	2.2	1.4
45-54	1.5	1.9
55-64	1.9	3.1
65-74	1.6	3.7
Total	1.75	2.1

It is difficult to compare incidence among similar age groups in different studies because of the different age intervals used. Eagan *et al*. reviewed data from several studies in 2005 and presented a comparison of the findings. Very few studies have comparable data to the present one in terms of the age groups covered. The paper by McWhorter *et al*.[21] has comparable data which can be seen in Table 6.

Table 7 presents data from different sources in order to allow a comparison with the PSPN study.

There are several questions arising from the high incidence of asthma in small children found here. There are considerable diagnostic difficulties in this age group. Often physicians diagnose asthma at an older age and retrospectively attribute the onset of asthma to a specific year. In the PSPN study the incidence rate in the age group 1-14 years was 3.74 cases per 1000 per year, considerably higher than the 1.4 cases/1000/year found by Yunginger *et al*. in 1992.[20] The PSPN study observed a higher incidence rate in the age group 0 – 4 years (5.93 cases/1000/year). It is possible that some of the children diagnosed with asthma were suffering from recurrent wheezing or bronchiolitis. These findings raise the possibility of over-reporting in this age group.

In this study, the incidence rate among patients over 65 years of age is 1.31/1,000/year. This is slightly higher than the incidence found in the USA in 1997.[20] Eagan *et al*. also suggest that the incidence of asthma in the elderly has previously been under-estimated.[5]

Our findings follow the pattern reported previously – with higher rates of asthma in boys than in girls and lower rates in men than in women.[22]

Accuracy of diagnosis

Given the difficulties in diagnosing asthma, one of the aims of the present study was to validate the diagnosis of asthma made by GPs working in the primary health care setting. While a number of studies suggest that there is under-diagnosis of asthma in children, adolescents and adults, little research has been conducted on the over-diagnosis of asthma. Symptoms similar to those seen in asthma can be found in other lung diseases such as emphysema and chronic

Table 7. Comparison of asthma incidence rate between the PSPN study and other studies.

Author / year	Location	Age group	Incidence rate /1000	PSPN 2004
McWhorter, 1988[21]	USA (NHANES I)	25-74	2.1	1.75
Yunginger, 1992[20]	USA	1-14	1.4	3.7
Bauer, 1997[16]	USA	>65	0.9	1.3
Ronmark, 1997[32]	Sweden	35-66	5	
Huovinen, 1999[17]	Finland	18-45	1.6	
Basagaña, 2001[19]	Spain	20-44	5.5	
Eagan, 2002[33]	Norway	15-70	3.2-3.6	
RHINE Study, 2004[34]	Sweden, Norway, Denmark, Iceland and Estonia	30-54	2.2	
de Marco, 2005[35]	Italy	20-44	1.5	
Eagan, 2005[5]	Several countries	Several (pooled data)	3.6-4.6	
Thomsen, 2005[36]	Denmark	12-41	5.5	

bronchitis.[23] These symptoms may also appear in patients with cardiac failure, pulmonary tumours or hyperventilation syndrome. The diagnostic accuracy found in this study was 83.9%. This figure is lower than that found by Ward *et al*.[24] whose sample was limited to individuals aged 16 – 45 years in order to reduce the effects of diagnostic uncertainty in children and confusion with COPD in older patients. This may explain the difference in the rates.

The accuracy of diagnosis in the present study was higher than that found by Montnémery *et al*. (76.5%),[25] but their study involved over 100 general practices compared to 43 physicians in the current study – and this might explain the differences in diagnostic accuracy between the two studies. Marklung *et al*. reported a diagnostic accuracy of 66% over a two year period,[23] but their study involved only 86 patients compared to 310 in the current study.

We used existing international guidelines[8] for the definition and diagnosis of asthma when the first report of the study was completed in 2005. Due to the limitations of guidelines,[26,27] the difficulties encountered by physicians in adhering to them,[28] and difficulties in clinical practice in managing asthma in line with recommendations,[29] the International Primary Care Airways Group (IPAG) produced its own guidelines for primary care physicians in 2005.[30] Together with the IPCRG guidelines,[14] these provide a more practical approach than the GINA Guidelines. They add clinical assessment, continuity of care, and the best knowledge of the family history to help make the diagnosis of asthma. The IPCRG recommendations[14] remain an excellent tool for the management of asthma and other respiratory conditions in primary care even after publication of the 2006 GINA update.[31]

Implications for future research

This study has implications for clinicians, researchers and patients. A incidence of 2 new cases per 1000 persons per year with a diagnostic accuracy of 62% suggests that there is considerable under-diagnosis of a common, treatable condition. Patient education to improve recognition and reporting of important symptoms to their physicians, and education of practitioners in the use of valid diagnostic criteria, may help increase the rate of diagnosis and improve patients' quality of life by providing them with effective treatment. Further research that focuses on effective education for the public and healthcare professionals, and effective application of existing standards for the diagnosis and treatment of asthma, is also required.

Conclusion

Data from the current study suggest that the diagnoses of asthma made by the family physicians in the PSPN were accurate in 84% of all reported cases with reference to the diagnostic criteria used. The incidence rate reported here falls within the range of values reported in the literature from other countries. Based on these data we may expect 20,250 new cases of asthma per year in Portugal. If so, there is probably marked under-diagnosis of this condition in practice. This suggests the need for an educational campaign to make the diagnostic criteria more widely known and to provide support for practitioners in making the diagnosis. With the effective treatments now available, a campaign for more accurate diagnosis and the application of evidence-based guidelines for treatment would have the potential to improve quality of life for a large segment of the population.

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Conflict of interest declarations

Dr Correia de Sousa has received sponsorship to attend international meetings from Novartis and MSD and honoraria for lecturing and attending advisory boards from AstraZeneca and Altana. His department has received research funding from AstraZeneca. Dr Silva received sponsorship to attend local and international meetings from AstraZeneca and MSD.

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Asthma in an Urban Population in Portugal:
A prevalence study.

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Asthma in an Urban Population in Portugal: A prevalence study

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Abstract

Background: The prevalence and incidence of asthma are believed to be increasing but research on the true incidence, prevalence and mortality from asthma has met methodological obstacles since it has been difficult to define and diagnose asthma in epidemiological terms. New and widely accepted diagnostic criteria for asthma present opportunities for progress in this field. Studies conducted in Portugal have estimated the disease prevalence between 3% and 15%. Available epidemiological data present a significant variability due to methodological obstacles.

Aim: To estimate the true prevalence of asthma by gender and age groups in the population of the area covered by one urban Health Centre in Portugal.

Method: An observational study was conducted between February and July 2009 at the Horizonte Family Health Unit in Matosinhos, Portugal. A random sample of 590 patients, stratified by age and gender was obtained from the practice database of registered patients. Data was collected using a patient questionnaire based on respiratory symptoms and the physician's best knowledge of the patient's asthma status. The prevalence of asthma was calculated by age and gender.

Results: Data were obtained from 576 patients (97.6% response rate). The mean age for patients with asthma was 27.0 years (95% CI: 20.95 to 33.16). This was lower than the mean age for non-asthmatics but the difference was not statistically significant. Asthma was diagnosed in 59 persons giving a prevalence of 10.24% (95% CI: 8.16 to 12.32). There was no statistically significant difference in the prevalence of asthma by gender.

Conclusion: The prevalence of asthma found in the present study was higher than that found in some studies, though lower than that found in other studies. Further studies in other regions of Portugal are required to confirm these findings.

Keywords: Asthma, Prevalence, Portugal

Background

Asthma is a common chronic disease world-wide with a high prevalence in all age groups, mostly in children and young people yet there is wide variation in the prevalence of the condition between and within countries [1-8]. Asthma prevalence and incidence are believed to be increasing [9-11], though this view is controversial [2,12,13].

Asthma is also an important reason for hospital admission [14,15] and causes considerable limitations on the physical, emotional, social, and professional lives of both patients and their families, interfering with normal activity and quality of life [16,17].

Available epidemiological data on the incidence, prevalence and mortality from asthma present significant variability as research has met with methodological obstacles since it is difficult to define and diagnose asthma in epidemiological terms [2,18,19]. Some studies used non-standardized questionnaires while other included patients after a pulmonary function assessment or proof of bronchial responsiveness. Because of the differences in methodology, considerable differences of

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prevalence have been found in different studies. New widely accepted diagnostic criteria for asthma present opportunities for progress in this field.

The Global Initiative for Asthma (GINA) lists some actions required to reduce the burden of asthma. One task is to recognise asthma as an important cause of morbidity, economic cost, and mortality worldwide and to measure and monitor the prevalence of asthma, and the morbidity and mortality due to asthma throughout the world [2].

The Portuguese Asthma Control Program was developed in 2000 [20] and, in line with the GINA proposal, recommended regular studies on epidemiological and clinical follow up of asthma. The Portuguese Guidelines on the diagnostic and control of asthma, based on the existing GINA Guidelines, were also published in 2000 [21] and were updated in 2007 [22] after the 2006 changes of the GINA Report.

Several studies conducted in Portugal have estimated the disease prevalence as ranging from 3.3% to 15% [23-32]. Most of the Portuguese data available were obtained before 2006, covered limited age groups or were obtained using methodologies with questionable accuracy of the prevalence rates.

This study was conducted to determine the prevalence of asthma by gender and stratified age groups in the Horizonte Family Health Unit in Matosinhos Portugal in 2009 to increase our knowledge of the epidemiology of asthma.

Method

Study population

Matosinhos, Portugal is a suburb of the city of Porto with a population of 169,261 inhabitants in 2008. The age and gender distribution of Matosinhos is similar to that of the total Portuguese population [33]. The population of the *Horizonte* Family Health Unit is similar in age and gender distribution in turn to the population of Portugal (Additional file 1, Appendix 1 - Comparison of the practice population with the Portuguese Population).

The *Horizonte* Family Health Unit is a group practice formed by eight family physicians working together for more than ten years with a stable registered population. The change in the population of registered patients in the practice between 2008 and 2009 was an increase of 1.88%. There is a good accessibility to healthcare. Most patients can be seen by any of the partners in case of their personal doctor is absent with continuity of the electronic medical record. The unit is a training practice for basic medical education and postgraduate family medicine residency training programmes. These characteristics of the practice provide a unique opportunity for epidemiological studies.

An observational study was conducted between February and July 2009 at the Horizonte Family Health Unit. A stratified random sample by age and gender was obtained from the practice general database of 13,568 registered patients.

Justification of age strata

The study population was divided into four age strata: 0 to 7 years, 8 to 19 years, 20 to 64 years and over 65 years. The youngest age group of birth to 7 years was selected to represent the age when asthma tends to be most prevalent and hospital admission rates are higher. The second age group of 8 to 19 years was chosen to study the period when mortality from asthma has been found to be highest [34]. Adults aged 20 to 64 and the elderly aged 65 and over were studied separately because diagnostic problems regarding asthma are common in the elderly.

Sampling procedures

Based on the available published literature a prevalence of asthma was predicted in this population for the four age strata. In the 0 to 7 year age group a prevalence of 11% was predicted, for 8-19 years 11.8%, for 20 to 64 years 5%, and for over 65 years 5%. Using the method of Lehr [35], a sample size calculation was performed to determine the true prevalence of asthma in each age group plus or minus 2% with 95% confidence. In the 0 to 7 year age group 150 patients would be required, for 8-19 years 160 patients, for 20 to 64 years 140 patients, and for over 65 years 140 patients. Thus a sample of 590 patients would be required in this population.

The required number of patients was selected from each age group using the patient register in the practice and a random number generator.

Data collection

Data were collected using two questionnaires: a physician's questionnaire (Additional file 2, Appendix 2 - Physician Questionnaire) and a patient questionnaire (Additional file 3, Appendix 3 - Patient Questionnaire). The physician's questionnaire consisted of demographic information including the age and gender of each of the selected patients and clinical data on asthma. The first question was "does this patient have asthma?" If the answer was positive, the family doctor was required to answer four sets of questions. The first questions asked about the presence of wheezing. The second set assessed a past or present history of dry cough, recurrent wheeze, dyspnoea/ recurrent difficulty in breathing or recurrent chest tightness. The third set of questions assessed the evidence of reversibility of airflow obstruction after administration of a short acting bronchodilator through clinical observation only, peak flow measurement or spirometry. The fourth question asked if a diagnosis of asthma had been made by a secondary care specialist in case the diagnosis had not been made by the family doctor alone.

The patients' questionnaire was based on the ISAAC questionnaire [36] and consisted of demographic information including age and gender and 13 questions on asthma. Eight questions where about symptoms and used the ISAAC core questionnaire for wheezing and asthma. The first group of questions asked about the presence of wheezing at present and specifically in the last 12 months, the number of attacks of wheezing in the last 12 months, wheezing during or after exercising, and waking up because of wheezing or dry cough at night in the last 12 months. Patients were asked if they ever had asthma or if they had ever been told by a doctor that they had asthma. The second section consisted on five questions about medication. Questions were asked on the use of any form of asthma medication in the last 12 months and covered all the commercial alternatives available in Portugal including the colour and the brand names of both inhalers and tablets. An algorithm of diagnostic steps was used to make the diagnosis of asthma based on the responses obtained in the study questionnaires (Figure 1).

In the first phase of the study, between February and April 2009, all eight physicians in the health unit were asked to report on each of the selected patients that were seen during routine scheduled appointments for any clinical reason. Each family doctor completed the physician's questionnaire. Each patient was invited to answer a questionnaire based on respiratory symptoms and signed an informed consent form.

In the second phase, between April and July 2009, all the patients who had missed an appointment were contacted by phone and invited for an interview with the researchers, while the family physician was asked to fill in the doctor's questionnaire. Any patient who failed to answer the phone after three attempts or refused to participate was replaced by another patient with similar age and gender characteristics (next random number in the same age group). Patients who did not have any appointment during the first phase were also contacted by phone.

The diagnostic procedures were based on a combination of the answers given by the patient on respiratory symptoms and the physician's best knowledge of the patient's asthma status. If the family doctor answered "no" to the question "Does this patient have asthma?" and the patient reported the absence of asthma symptoms, it was considered that asthma was not present. If the doctor answered "yes" to the same question and the patient reported symptoms of asthma ("probable cases"), the diagnostic algorithm was used (figure 1) in order to confirm or reject the diagnosis. In cases of inconsistency between the information provided by the family doctor and the patient ("doubtful cases"), an interview was conducted by the researchers with an assessment of the patient to validate the diagnosis.

Data analysis

Data were entered on an electronic spreadsheet program and analyzed using Epi-Info version 3.5.1 software. The prevalence of asthma was calculated for the total population and for specific age groups by dividing the number of cases found by the size of the population. Standardized rates were computed using Portuguese census data for 2005 [33].

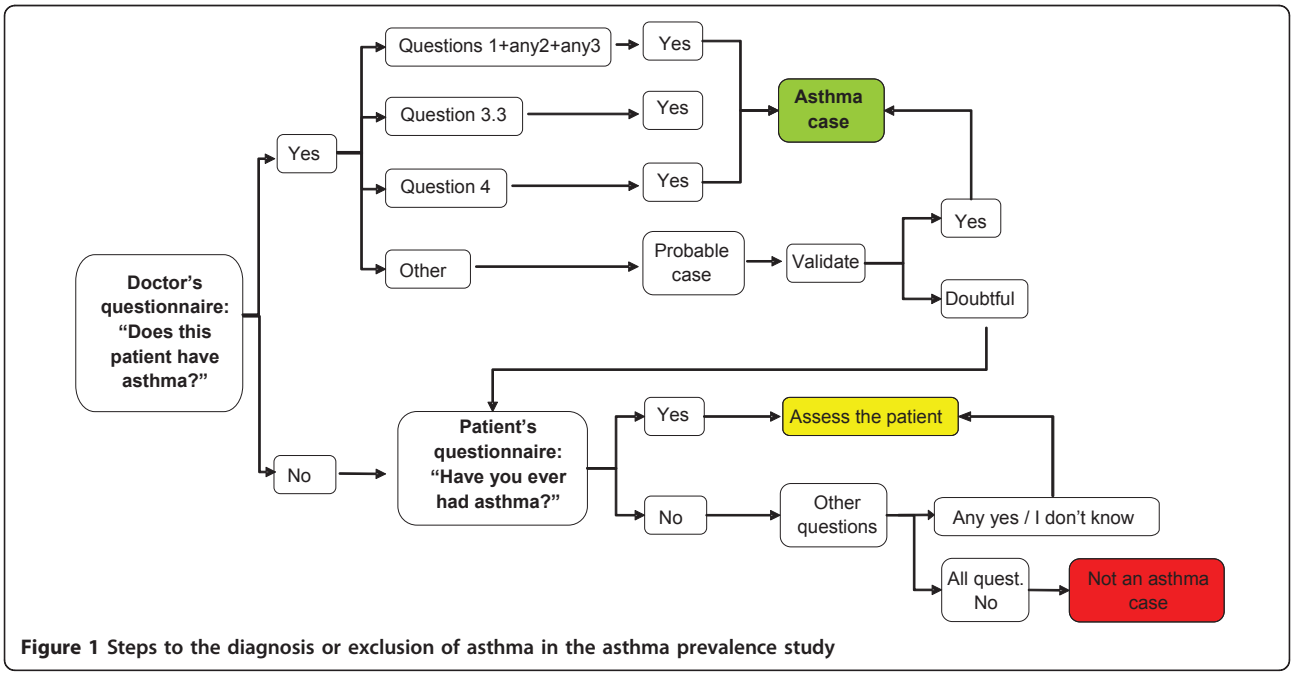

Figure 1 Steps to the diagnosis or exclusion of asthma in the asthma prevalence study

In order to assess the predictive value of the items used in the symptom questionnaire and the diagnostic algorithm described above for a diagnosis of probable asthma or doubtful asthma, odds ratios and 95% confidence intervals were calculated using the Epi-Info TABLES function. This was done to determine which items in the history were most likely to be associated with a final diagnosis of asthma.

Ethical approval

Prior to data collection, the study protocol was approved by the Ethics Committee of the Local Health Authority in Matosinhos (Unidade Local de Saúde de Matosinhos). Each patient invited to participate signed an informed consent form after the aims and methods of the study were explained. All new cases of asthma or uncontrolled cases found in the study were referred back to their family physician for treatment.

Results

From the stratified random sample of 590 patients selected from the population of the Horizonte Family Health Unit, data were obtained from 576 patients (for a response rate of 97.6%, Figure 2). The characteristics of the study population are given in Table 1.

The mean age of this population was 33.2 years (sd = 28.1 years; 95% CI: 30.9 to 35.5), and 297 (51.6%) of the patients in the sample were female.

Using the GINA criteria, asthma was diagnosed in 59 persons giving a prevalence of 10.24% (95% CI: 7.76 to 12.72).

A diagnosis of "probable asthma" was initially made in 37 patients (6.4%) and 102 patients were classified as "doubtful cases"

Following a medical record review and interview of doubtful cases, 22 were reclassified as asthmatic (for a total of 59 cases), 514 as healthy and 3 (0.5%) remained as doubtful cases.

The mean age for patients with asthma was 27.0 years (sd 23.4, 95% CI: 21.0 to 32.9). For non-asthmatics the mean age was 33.9 years (sd 28.5, 95% CI: 31.4 to 36.3). This difference was not statistically significant.

The mean age for male patients with asthma was 22.0 years (sd 17.8; 95% CI: 15.5 to 28.5) with a median age of 18.3 years. For males without asthma the mean age was 33.4 (sd 27.7; 95% CI: 29 to 36) with a median age of 19.7 years. This difference was statistically significant ($p < 0.05$).

The mean age for female patients with asthma was 34.2 years (sd 28.9; 95% CI: to 41.5) with a median age of 18.2 years. For females without asthma the mean age was 34.5 (sd 29.2; 95% CI: 31 to 38) with a median of 19.3 years. This difference was not statistically significant.

Female patients comprised 51.8% of the asthma patients. There was no statistically significant difference

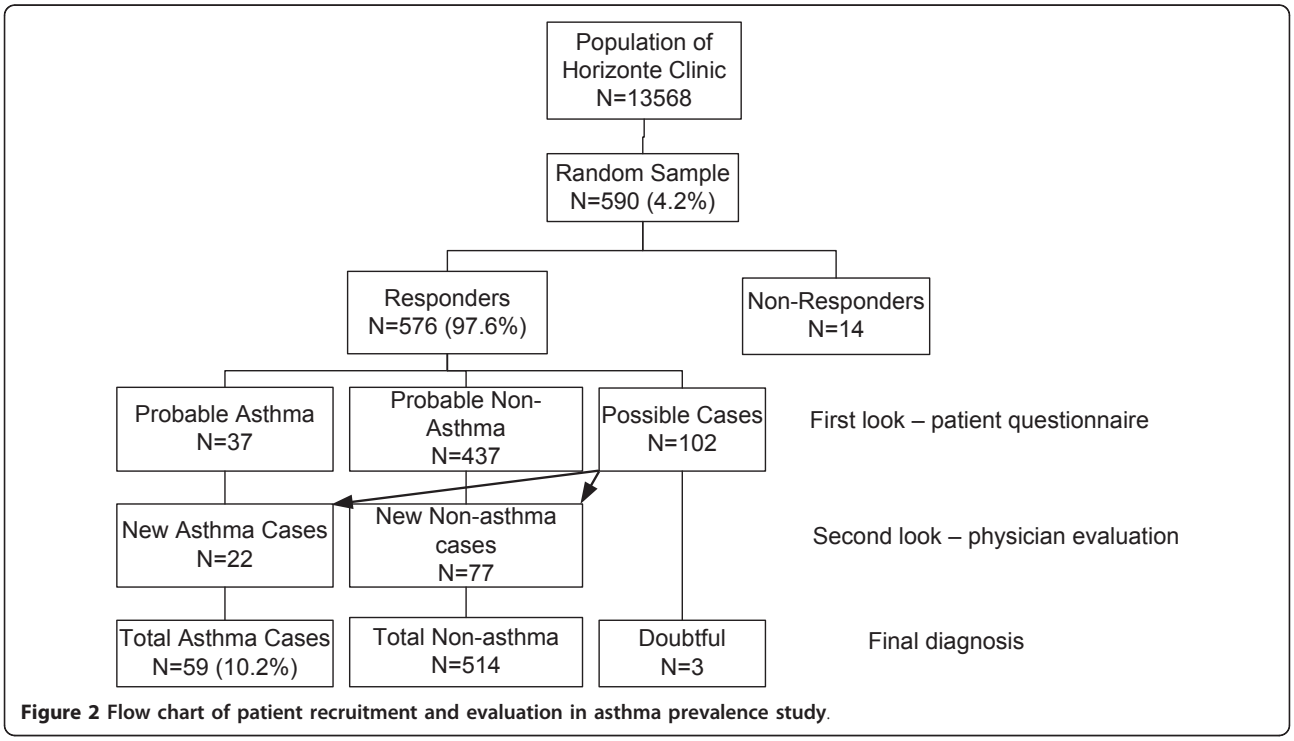

Figure 2 Flow chart of patient recruitment and evaluation in asthma prevalence study.

Table 1 Demographic characteristics of study sample by gender, age and diagnosis

	Total sample N = 576 Mean age	Asthma cases N = 59 Mean age	Non-asthma N = 517 Mean age
	33.2 years (s.d. 28.1)	27.0 years (s.d. 23.4)	33.9 years (s.d. 28.5)
Males	32.2 years (s.d. 27.1) N = 279 (48.4%)	22.0 years (s.d. 17.8) N = 29	33.4 years (s.d. 27.7) N = 250
Females	34.2 years (s.d. 28.9) N = 297 (51.6%)	31.8 years (s.d. 27.2) N = 30	34.5 years (s.d.29.2) N = 267

in the prevalence of asthma by gender for the total population.

Among young children under the age of 8 years the prevalence of asthma is higher in males (13%) than in females (7%) but this difference is not statistically significant in this population (OR = 2, 95% CI, 0.6 to 6.9).

Among patients over 65 years of age the prevalence is higher in females (7.3%) than in males (1.7%) but this difference is not statistically significant (OR = 0.2, 95% CI = 0.004 to 1.9).

Asthma prevalence by age group in the sample population and standardized for the Portuguese population is given in table 2.

Associations between symptoms and diagnosis

The association between positive symptoms elicited in the patient questionnaire and a final diagnosis of asthma was tested by computing the odds ratio (OR) for a positive reply comparing true cases of asthma with doubtful cases (Table 3). The following items were found to be statistically significant: wheezing after exercise (OR 4.2), waking up from wheezing (OR 3.4), a personal history of asthma (OR 12), being told by a doctor that the patient has asthma (OR 14.6), use of a short-acting beta agonist in last 12 months, (OR 35.6), use of a long-acting beta agonist in last 12 months (OR 7.6), and the use of an inhaled steroid in last 12 months (OR 25).

Discussion

This study found that the prevalence of asthma in the population of the area covered by the Horizonte Family Health Unit in Matosinhos, Portugal was 10.24% using data collected from a random sample of the registered population.

In Portugal, the composition of the population of patients registered on the lists of general practitioners is very similar to the general population living in the region. This was described in a recent publication on the incidence of asthma using general practice populations [37]. The population described in the general practice in current study is believed to be representative of Matosinhos therefore these findings are believed to represent the prevalence of asthma in this population.

Internal validity

The findings of this study are believed to represent the true prevalence of asthma in this population. This is due to use of a stratified random sample drawn from accurate patient lists with a good response rate. In the case of non-responders, replacements were drawn from a list of alternates also produced by the random number generator. The use of accepted diagnostic criteria validated by additional interview and examination by physicians in cases of doubt regarding the diagnosis also increases confidence in the quality of the data. In some age groups the wide confidence intervals for the prevalence of asthma is due to the small numbers of cases found. A similar study in a larger population will resolve this issue further.

Study questionnaire and diagnostic criteria

The patient questionnaire was based on the Portuguese version of the ISAAC questionnaire which had been previously used in Portugal as part of an international

Table 2 Asthma prevalence by age group in the sample population and standardized for the Portuguese population

Age groups	Asthma	Non-asthma	Prevalence %	95% CI	Prevalence % Standardized for Portuguese Population
0 to 7	13	123	9.56	5.41 to 13.71	8.6
8 to 19	21	139	13.13	8.74 to 17.52	13.1
20 to 64	18	122	12.86	8.21 to 17.51	12.3
≥ 65	7	133	5.00	1.97 to 8.03	6.3
Total	59	517	10.24	8.16 to 12.32	
Total sample		576			

(The three "doubtful cases" were included with the non-asthma patients in this table.)

Table 3 Odds ratios for the association of positive symptoms with a diagnosis of asthma

From the patients' questionnaire, the following items were positive:	Asthma cases (n = 59)	Doubtful cases (n = 39)	O.R. (95% CI)
Any history of wheezing	57 (96%)	38 (97%)	
Wheezing in the last 12 months	40 (67%)	22 (26%)	
Wheezing after exercise	19 (32%)	4 (10%)	4.2 (1.2-18.1)
Wake up from wheezing	23 (39%)	6 (15%)	3.4 (1.1-11.7)
Night time dry cough	40 (67%)	20 (51%)	
Personal history of asthma	45 (76%)	8 (20%)	12 (4.2-37.9)
Told by a doctor they have asthma	47 (80%)	8 (20%)	14.6 (5-47)
Use of SABA in last 12 months	29 (49%)	1 (3%)	35.6 (5-1358)
Use of LABA in last 12 months	10 (17%)	1 (3%)	7.6 (1.00-345)
Use of Inhaled steroid in last 12 months	24 (40%)	1 (3%)	25 (3.7-1099)
Use of LABA-steroid in last 12 months	4 (7%)	1 (3%)	
Use of leukotriene in last 12 months	11 (19%)	0	

study [4]. (The authors used only the relevant questions about asthma symptoms from the questionnaire.)

The physician questionnaire was constructed using the guidelines in the GINA 2006 Report [38]. Questions were asked about the presence of wheezing, past or present history of dry cough, recurrent wheeze, dyspnoea/recurrent difficulty in breathing or recurrent chest tightness and the evidence of reversibility of airflow obstruction after administration of a short acting bronchodilator through clinical observation only, peak flow measurement or spirometry. The same questionnaire was used in a study on the incidence of asthma and accuracy of diagnosis in the Portuguese sentinel practice network [37]. The utility of this questionnaire in these two studies suggests that future study of asthma prevalence could also use these diagnostic criteria.

Comparison of findings with other published studies

There are many published studies on the prevalence of asthma but the absence of a precise and universally accepted definition of asthma makes reliable comparison of reported prevalence from different parts of the world problematic [2].

Portuguese studies

The prevalence of asthma found in the present study for the general population was considerably higher than that found in previous studies in Portugal though different methodologies and age groups have been used. Care is required in comparison of these results with findings from other studies. In the survey published in 1987 by Nunes et al [24] for patients aged 7 to 17 years observed regularly using a symptom score and spirometry, a prevalence of 3.4% was found. In 1990 Chieira et al [25] studied 557 twenty year old male conscripts using a questionnaire and clinical observation and found a prevalence of 5.2%. In 1991 Marques [39] studied a random sample of 2000 inhabitants of the city of Porto aged 20 to 44 years using the ECRHS questionnaire and found a prevalence of 4.3%. In 1992 Nunes et al [26] published a report on 55,254 subjects in Algarve, Portugal using a questionnaire and found a prevalence of 5.5% among patients attending primary care consultations. In 1994 Alves et al [23] published the results of a survey in the city of Porto using a postal questionnaire and found a prevalence of 3.1% for the diagnosis of asthma and 6.45% for asthma symptoms in persons of both genders aged 18 to 44 years. In 1994 Prata et al [27] studied 927 children 6-12 yrs old in Faial, Azores, and met a prevalence of 8.0%. In 1995 Vicente et al [28] studied 17,200 students aged 12-19 yrs living in eight major cities in Portugal and found a prevalence of 3.2%. In 1996 Morais Almeida et al [29] used a questionnaire to study a sample of 1,061 children aged 6-10 yrs in the Madeira Island, Portugal and met a prevalence of 15%. In 1998 Leiria Pinto P et al [30] studied 1,334 adolescents aged 12-16 yrs living in Lisbon using a questionnaire and found a prevalence of 11.4%.

The 2005 Portuguese National Health Survey [40] found an overall asthma prevalence of 5.5%. The method used for data collection was a home interview of a stratified representative sample of the Portuguese population with self-report on the conditions of interest. In 2005 Branco et al [31] used a telephone interview with a random sample of 1,211 households in mainland Portugal and a total of 2,820 subjects of all ages as part of a survey of chronic conditions. The prevalence of self-reported asthma was 8.6%. Table 4 displays a comparison of asthma prevalence rates for all age groups and methods in Portuguese surveys.

International studies

The comparison of the Matosinhos survey results with other international data confirms that they are close to

Table 4 Comparison of asthma prevalence rates for all age groups and methods in Portuguese surveys

Year	Study	Prevalence %	Method
1992	Nunes et al [26]	5.5	Questionnaire
2005	Branco et al [31]	8.6	Self-report/Interview
2006	Portuguese National Health Survey [40]	5.5	Self-report/Interview
2009	Correia-de-Sousa et al	10.2	Questionnaire, self-report of symptoms

published values. According to data from the World Health Survey from 2003, [41] the prevalence of diagnosed asthma showed a narrow range across countries. There was a 10-fold variation in current wheezing symptom prevalence across countries (2.4% in Vietnam and 24.3% in Brazil). The majority of estimates fell within a fourfold range of prevalence, with Vietnam the lowest at 1.8% and Australia the highest at 32.8%.

The 2003 Global Burden of Asthma document [3] published on behalf of the GINA project compares the mean prevalence of clinical asthma in different regions. It ranges from 2.1% in Central North Asia (China/Taiwan/Mongolia) to 16.1% in the United Kingdom and Republic of Ireland. Prevalences are higher in North America, Oceania and West and Eastern Europe than in Asia or Africa. Southern Africa (8.1%) and South America (9.9%) have intermediate prevalences. The prevalence given for Western Europe (including Portugal) is 5.9%, lower that the data from the Matosinhos study. These studies have gathered data from different sources and present a rather different range of values.

The most recent publications suggest that asthma prevalence ranges from 7.2% to 12.2%. In the U.S. National Surveillance for Asthma study published in 2007 the overall prevalence of asthma was 7.2% [42]. A Germany study from 2005 by Stock et al [43] shows a total prevalence of asthma of 6.34% in the study population. A study from South Australia from 2006 by Wilson et al [44] shows that asthma prevalence increased from 7.5% to 12.2% from 1990 to 2003. In a Swedish study from 2009 by Lötvall et al [45], asthma prevalence, defined as asthma diagnosed by a physician, was 8.3%. In a Norwegian study from 2003 by Brogger et al [46], the crude prevalence of ever having had a doctor's diagnosis of asthma increased from 3.4 to 9.3% from 1972 to 1998-99. Table 5 presents a comparison of published international asthma prevalence rates.

Comparison of prevalence by age groups

In the United States National Surveillance for Asthma, the prevalence rate among the birth to 4 year age group was 5.9% [42]. A study among kindergartners in Chicago public schools (mean age 5.7 yrs) found a prevalence of asthma of 10.8% [47]. Data published by The Los Angeles County Health Survey [48] shows a prevalence of asthma in the birth to 5 years group of 5.9%. Martinez et al. [49] studied wheezing before the age of three years and the relation to wheezing at six years of age and found that at the age of six years 13.7% of the studied children had wheezing both before three and at six years of age. Children with persistent wheezing had significantly reduced lung function. According to data from the New York State Asthma Surveillance, children from birth to 4 years in New York State had an asthma prevalence of 7.5% in 2006-2008 [50]. In a study carried out in Asturias, Spain, asthma prevalence calculated for infants was 7.6% [51]. In the Matosinhos survey, asthma prevalence in the birth to 7 years age group was 9.59%, close to figures found in published data.

In the study from 2008 by Ramos et al [32] in a sample of 13 year old urban adolescents the lifetime prevalence of asthma was 12.9%, with 84.4% of the diagnoses confirmed by a physician. In the Matosinhos survey, the prevalence in the age group 8 to 19 years was 13.13%. In the study by Nunes [24] the prevalence for a similar age group (7 to 17 years) was 3.4%. Vicente et al [28] found a prevalence of 3.2% in those aged 12 to 19 years old. In the age group 20 to 64 years, our study showed a prevalence of 12.86% while other Portuguese surveys found a prevalence of 3.1% and 4.3% [23,39]. There were no Portuguese data found for comparison of either the lower age groups (0 to 7 years) or for the elderly (over 65 years).

A Swedish study from 2006 [52] in children aged 7 to 8 years reported an increase in prevalence from 1996 to 2006 from 5.7% to 7.4%. In New Zealand the prevalence of asthma is considerably higher. In the ISAAC Phase Three study by Asher et al [53] repeating the questionnaire survey of two age groups of school children (6 to7 years and 13 to 14 years), the prevalence rates found

Table 5 International comparison of asthma prevalence rates for all age groups

Year	Study	Country	Prevalence %
2003	Brogger et al [46]	Norway	9.3
2005	Stcok et al [43]	Germany	6.34
2006	Wilson et al [44]	Australia	12.2
2007	National Surveillance for Asthma US [42]	USA	7.2
2009	Lötvall et al [45]	Sweden	8.3
2009	Correia-de-Sousa et al	Portugal	10.2

were 30.2% and 32.4% respectively. The results of Phase III of the International Study of Asthma and Allergies in Childhood (ISAAC) [12] in the age groups 6 to7 years and 13 to 14 years provide data for international comparison of prevalence rates for asthma and wheezing. The Portuguese data from this study show a mean lifetime prevalence of asthma in the age group 6 to7 years of 9.8% and 13.2% for the 13 to 14 year age group. These results are similar to our findings. The U.S. National Surveillance for Asthma study [42] found the prevalence to be 8.5% among those under 18 years and 6-7% for those over 18.

The U.S. National Health and Nutrition Examination Survey (NHANES III) [54] found an asthma prevalence on the age group over 20 years of 4.5%. In the Danish survey by Browatzki et al [55] published in 2009, the prevalence of self-reported asthma in the age group 20 to 35 years was 6.9%.

In the U.S. National Surveillance for Asthma study [42] the lifetime prevalence of asthma in individuals over 65 years of age was found to be 6.8%, though the percentage of elderly patients with "current" asthma was 5.9%. In the NHANHES III survey [54], the prevalence over 60 years was 3.6%. In our study, the prevalence for the over 65 age group was 5%.

The comparison of the findings of the current study with other studies computing lifetime prevalence of asthma is relevant because the current study included questions assessing if the patent had ever been told they had asthma.

Comparison of asthma prevalence by gender

Some studies report a clear gender difference [52,56], considering male gender to be associated with the increased risk of asthma in children. Prior to the age of 14, the prevalence of asthma may be nearly twice as great in boys as in girls [2].

In the present study there was no statistically significant difference in the prevalence of asthma by gender, though, among young children under the age of 8 years the prevalence of asthma is higher in males (13%) than in females (7%) but this was not statistically significant. Branco et al [31] also found no significant gender differences in asthma prevalence. This study was most similar to the Matosinhos survey. In some Portuguese surveys the overall prevalence for females is higher than for males [39,40], while in other the reverse was observed [32].

The U.S. National Surveillance for Asthma study [42] shows a difference in prevalence by genders with 8.1% among females and 6.2% among males. The report from the ISAAC phase I and III studies in Spain [56] shows a difference in prevalence by gender. In the age group 6 to 7 years, girls had 9.0% and boys 12.9%. In the age group 13 to 14 years, girls had 11.8% and boys 13.8%.

The Danish study of the prevalence and severity of asthma in young Danish adults over three decades shows a higher female prevalence in all the three phases. The female to male ratio was 1.7/1.2 in 1978, 4.8/4.5 in 1994 and 7.7/5.9 in 2004 [55].

Discussion of methods

Using the best knowledge about asthma from both the patient and the physician was also used in a Swedish study published in 2005. The authors concluded that a combination of a medically verified asthma diagnosis using medical records and the use of self-reported symptoms with the ISAAC questionnaire seem to be valid and reliable for the follow-up childhood asthma in the community [57]. This is the method we chose for diagnosis in our study and it seems to be a feasible method for increasing diagnostic accuracy. It may explain the higher prevalence found in our study compared to other Portuguese studies.

Implications

The findings of the current study suggest that asthma might have been under-reported in other epidemiological studies in Portugal. This may also be true in other countries. The use of accepted diagnostic criteria using the best knowledge from both the doctor and the patient may help to overcome this.

Careful assessment of symptoms can lead to more accurate diagnosis of population. Skilful application of this method in clinical practice may help to identify those patients who may benefit from appropriate treatment.

Conclusions

Use of the best knowledge about asthma from both the patient and the physician seems to be a good strategy for the determination of the prevalence of asthma in a community survey.

The prevalence of asthma found in the present study was higher than that found in some studies, though other studies have found a prevalence above 10%.

The prevalence of asthma in the birth to 7 age group was lower than expected due to diagnostic problems.

Based on these data, assuming a prevalence of asthma of 10%, with the current population of Portugal of 10,893,010 in 2011, we may expect 1,089,301 persons to have asthma in Portugal.

Further studies in other regions of Portugal using the same diagnostic criteria and sampling methods should be done in order to confirm these findings.

Additional material

Additional file 1: Appendix 1: Comparison of the practice population with the Portuguese Population

Additional file 2: Appendix 2: Physician Questionnaire
Additional file 3: Appendix 3: Patient Questionnaire

List of abbreviations used

GINA: Global Initiative for Asthma; ISAAC: International Study of Asthma and Allergies in Childhood; OR: Odds ratio; CI: Confidence interval;

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Authors' contributions

JCS conceived the idea for the study, designed it, collected data and wrote parts of the introduction, methods, results and discussion sections of the manuscript. ME, TC and FAL participated in the design, collected data and contributed to the writing of the methods and results section. JY performed the data analysis and wrote parts of the introduction, methods results and discussion. All authors read and approved the final version of the manuscript.

Competing interests

No conflicts of interests are reported for this study.
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Enablement and quality of life in asthma patients (the EQLAP study): a cross-sectional study from a family practice

Enablement and quality of life in asthma patients (the EQLAP study): a cross-sectional study from a family practice

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Abstract

Background:

There is evidence that self-assessment of asthma by patients and a stronger doctor-patient relationship can improve therapeutic compliance and improve asthma outcomes. Evidence is lacking on the influence of patient empowerment on the quality of life and control of asthma. The objectives of the current study were to assess asthma severity, medications, control, patient enablement and quality of life among asthmatic patients treated in primary care, and to study the relationship between enablement and quality of life.

METHODS: A cross-sectional study was conducted in an urban Family Health Unit in northern Portugal. Data were collected from both clinical records and questionnaires administered to a stratified random sample of asthma patients treated in this clinic. The Patient Enablement Instrument (PEI) the Asthma Quality of Life Questionnaire (AQLQ) and the Asthma Control Test (ACT) were used. Peak expiratory flow (PEF) and forced expiratory volume at one second (FEV1) were measured. The associations between patient empowerment, asthma control and quality of life were tested using logistic regression models.

RESULTS: The study sample included 180 patients treated by 7 physicians. Persistent asthma was found in 57% and 43% had intermittent asthma. PEI scores were higher among patients with intermittent asthma compared to those with persistent forms ($p<0.01$). There was a strong correlation between asthma control and quality of life ($r=0.81$, $p<0.001$). Patient enablement did not correlate with the results of the pulmonary function tests. A weak but significant association between patient enablement and asthma control and quality of life was found in the logistic regression models. Poor control of asthma was associated with female gender, concomitant co-morbidities, reduced FEV1 and increased severity of asthma. Poor quality of life was associated with female gender and severity of asthma.

CONCLUSIONS: The weak correlation between patient enablement and asthma control requires further study to determine if improved patient empowerment can improve asthma outcomes. This study shows how gender, severity and concomitant co-morbidities relate to asthma control and quality of life. It also confirms the strong correlation between asthma control and quality of life.

KEY WORDS: Asthma, Enablement, Quality of life

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Introduction

Asthma is a major public health problem and is one of the most prevalent chronic diseases in children and young people with significant effects on quality of life. Asthma prevalence and incidence are believed to be increasing. [1-3] Asthma is an important cause of hospital admission. It causes frequent distress at several levels, sometimes on a daily basis. It often affects the patient's family and may cause considerable limitation of the patient's normal daily activities.

Patient empowerment and self-control of asthma have recently received more attention in the medical literature [4-6] as in other chronic diseases. [7, 8]

One of the strategies proposed in the Global Initiative for Asthma (GINA) [2] to improve the control of the condition is the development of a partnership between physicians and other health professionals and patients with asthma, empowering patients to accept responsibility in the follow-up and self-control of their condition.

The Portuguese National Asthma Control Program [9] was developed in 2000 in line with the GINA proposal. Its aim was to reduce the prevalence, morbidity and mortality related to asthma in Portugal and to improve the quality of life and well being of asthma patients. The Portuguese Guidelines for the diagnosis and control of asthma, based on the existing GINA Guidelines, [10] were also published in 2000 [11] and were updated in 2007 [12] after the 2006 changes in the GINA Report. The program and the guidelines recommend improvements in the efficacy and efficiency of the delivery of health care to asthma patients in order to promote self-control of their condition. [9, 12]

Well organised health teams practising patient centred care together with more enabled and more independent patients in the management of their condition may obtain better results in the control of some chronic diseases, lowering morbidity, mortality and the health costs. This has led to the development of global management programs for these diseases, such as the St. Vincent Declaration for diabetes mellitus in 1989, [13] the GINA program for asthma in 1993, [10] and the GOLD project for COPD in 1997. [14]

There is some evidence that training patients in self-assessment through the use of a peak flow meter and the recording of symptoms together with regular consultations with health professionals and a written action plan can improve the results of treatment in adults with asthma. [2, 15]

Asthma control can be measured using the *Asthma Control Questionnaire* (ACQ) [16-18] or the *Asthma Control Test* (ACT). [19, 20] These questionnaires provide the patient and the physician with measures of the level of control of the disease and the need to adjust treatment.

It is also important to assure the quality of life of patients with asthma. The *Asthma Quality of Life Questionnaire* (AQLQ) [21] has been translated and validated for use in the Portuguese population. [22, 23]

Asthma has a negative effect on Health Related Quality of Life (HRQL). [24, 25] It is important to monitor this factor. The existing guidelines for asthma advise the involvement of patients in care through the use of flexible self-management plans, as often as possible. [26] Allowing the patients the opportunity to improve their knowledge and understanding of asthma can improve trust in their treatment, leading to better adherence to the therapeutic plan.

Patients with asthma have often low expectations about control of the illness. They may adapt to the effects of poor control of asthma until they are given information that shows them that they can do better. Many patients are receptive to the use of written and personalised action plans. The implementation of such plans, supported by adequate education, and the improvement of health literacy can help patients to achieve a better control of asthma. [27]

The Patient Enablement Instrument (PEI) is a tool to measure satisfaction with the result of consultations. It was developed by Howie et al. in 1998. [28] Its purpose is to assess patient enablement in the control of an acute or chronic disease as a result of a consultation. It can also be used as a measure of the individual performance of a physician. While satisfaction is described in relation to the patient's expectations, enablement is a condition where gains are obtained for the patient. Haughney et al. developed the mPEI, a modification of the *Patient Enablement Instrument,* for the assessment of enablement of patients with asthma. [29]

The management of chronic diseases presents important challenges for doctors, including primary health care physicians. [30-32] It is possible that the model of patient centred health care in use in family medicine, [33] has fostered the development of more independent patients with a higher level of control over their disease. [34]

International guidelines like the GINA project [2] suggest that a stronger doctor-patient relationship can improve adherence to treatment plans and lead to better results in asthma management. It is necessary to identify the factors that influence the level of enablement and quality of life in a population of patients with asthma to test this hypothesis.

The objectives of the current study were to assess the severity of asthma, medication use, asthma control, the level of patient enablement and the quality of life in a population of asthmatic patients treated in primary care, and to study the relationship between enablement and the quality of life of asthma patients.

Method:

Study population

Matosinhos, is a suburb of the city of Porto in northern Portugal with a population of 169,261 inhabitants in 2008. The age and gender distribution of the population of Matosinhos is similar to that of the total Portuguese population. [35] The population of the Horizonte Family Health Unit is similar in age and gender distribution in turn to the population of Portugal.

Practice Setting

The Horizonte Family Health Unit is a group practice formed by eight family physicians working together for more than ten years with a stable registered population. There is good accessibility to healthcare. Most patients can be seen by any of the partners when their personal doctor is absent with continuity of the electronic medical record. The unit is a training practice for basic medical education and postgraduate family medicine residency training programmes. These characteristics of the practice provide a unique opportunity for clinical and epidemiological studies.

The study questionnaire was pilot-tested in 20 patients to examine content and face validity between January and March, 2010.

A cross-sectional study was conducted between February and November, 2010 at the Horizonte Family Health Unit.

Sampling procedures

A stratified random sample of asthmatic patients was obtained from the practice database of 450 asthmatic patients 18 years or older from the list of seven GPs. A diagnosis of asthma had been previously established by each of the family physicians. The definition of an asthma case for selection for the data base was made according to the GINA report [2] as explained in the paper published by the authors in 2010. [36] This data base had been used for several studies, and was therefore fairly accurate, though some minor inclusion errors had occurred. When patients were invited for the interview they also confirmed having asthma, either because they had previously been told so by their GP or another physician or were receiving asthma medication. A few patients that had been incorrectly selected for the data base and had other conditions, such as COPD, where excluded and replaced by the next subject in the sample.

A random sample of 180 patients with asthma was obtained by simple replacement method using Randomizer.org. Patients with kyphoscoliosis, congenital or acquired absence of one lung, lung cancer, or cognitive impairment, pregnant or bedridden patients, or anyone unable to answer the questionnaire were excluded. There were five attempts to contact the selected patients. Whenever it was not possible to reach a selected person or patients were unable or unwilling to come to the practice for an interview, they were replaced by the next patient with the same age and gender from the list.

Questionnaires and tools

The authors developed a questionnaire to collect demographic and clinical data from the interviews and used standardised questionnaires – the mini ACT, the modified PEI and MiniAQLQ. The demographic data was based on the questions that form the Graffar Social Classification, [37] a tool often used in Portuguese population studies. The clinical data section was based on the GINA classification of levels of severity and the several categories of drugs used to treat asthma.

The Mini Asthma Quality of Life Questionnaire is a questionnaire designed for most patients to complete on their own. The questionnaire contains 15 items. All items are equally weighted. The overall Mini-AQLQ score is the sum of the scores for each item, divided by 15 (the number of items). The overall score is expressed as a score out of 7. A change in score of greater than 0.5 can be considered clinically important. [22, 38]

The modified Patient Enablement Instrument adapted by Haughney et al. [29] to evaluate "enablement" in patients with asthma was used in the survey. The original English version was first translated to Portuguese and then back to English by two bilingual professional translators. The second translator did not read the original English text. The analysis of the back translation matched the original version. The resulting questionnaire was then applied to a pilot sample of 30 patients to asses the linguistic and cultural understanding of the questions and this was found to be satisfactory. A PEI score $\geq$ 6 has been reported as indicating clinically meaningful enablement.

The researchers have standardized the instructions for patients and these were asked to do at least three correct manoeuvres of FEV1 and PEF measurement, the best one being chosen. Manoeuvres were performed in standing position. No nose clip was used.

Data collection

Data were collected using medical records and a questionnaire produced by the authors. Participants were contacted by telephone or in person, informed about the research objectives and invited for an interview. Those who agreed to participate provided written informed consent. In case of difficulty in reading or understanding the questions, the investigator helped with the interview.

The demographic data collected and analysed included gender, age, and social rank on the five-point Graffar scale. This scale includes questions about occupation, education, household income, housing, and social status of the neighbourhood. The severity of asthma was assessed according to the criteria defined by the GINA 2008 update. Medications used for relief and control of asthma were coded with the glossary of anti-asthmatic therapy created by GINA. Asthma control was assessed as full control, partly controlled and uncontrolled using the mini Asthma Control Test, validated for patients over the age of twelve. Quantitative assessment of asthma control was made by measuring peak expiratory flow (PEF) and forced expiratory volume at one second (FEV1) using the Piko-1® spirometer which has been validated for use in Portugal. [39,

40] Concomitant comorbidities were counted. Quality of life was measured with the Mini-AQLQ (Asthma Quality of Life Questionnaire).

Statistical analysis

Data were collected, reviewed and coded into the spreadsheet program Microsoft Excel®. For the statistical analysis the authors used EpiInfo ® (version 3.4) and the PASW Statistics for Windows ® (version 18.0). Data are presented by mean, median, standard deviation and range. Student t-test or the equivalent non parametric test of Man-Whitney were used for the comparisons between two groups. Several groups were compared using Analysis of Variance or the non parametric test of Kruskal-Wallis. Categorical data were analysed by the Chi-square test. Pearson and Spearman rank correlation coefficients were used to study the associations between several variables under study. Receiver Operating Characteristic Curve analysis was used to define a cut-off on quality of life as a classification of good and poor asthma control. Logistic regression models were used to study the relation between several independent variables and the dependent variables quality of life and ahstma control. Statistical significance was set for $p<0.05$.

Ethical approval

Prior to data collection, the study protocol was approved by the Ethics Committee of the Local Health Authority in Matosinhos (Unidade Local de Saúde de Matosinhos). Each patient invited to participate signed an informed consent form after the aims and methods of the study were explained. All cases of uncontrolled asthma found in the study were referred back to their family physician for treatment.

Results:

From the stratified random sample of 180 asthma cases drawn from the clinic population, complete data were obtained from 175 cases for a response rate of 97.2%. The characteristics of the patient population are given in Table 1.

The study population was composed of 68% female patients. The mean age of patients was 45.9 years, with a standard deviation of 17.1 years, a median age of 46.0 years, and a range of 18 to 83 years. Interaction between age and gender in the EQLAP study sample was tested using the Student t-test. The mean age for males was 41.1 years (sd 16.2) and for females the mean age was 48.1 years (sd 17.2). The difference of seven years in the mean age between genders was statistically significant ($p<0.05$). Therefore it was necessary to control for age and gender in other analyses of association between predictor and outcome variables in this study.

Table 1: Characteristics of the study sample by gender and age

	Males	Females	Total
n (%)	56 (32%)	119 (68%)	175
Mean age (years)	41.1	48.2	45.9
Median age	38.0	49.5	46.0
Mode	19	29	19
Range	19 to 74	18 to 83	18 to 83
Standard deviation	16.2	17.2	17.1

The patients selected in the original sample who were unavailable for study (non-responders) were analysed by age and gender to look for possible sources of bias. There were 38% males and 62% females among the non-responders which was similar to the gender distribution in the responders' group (Chi squared statistic =0.5, $p>0.05$). The mean age of non-responders was 48.1 years (sd 21.2) and the mean age of responders was 45.9 years (sd 17.1). This difference was found to be non-significant ($p>0.05$) by the Student t-test (Tables 2, 3 and 4).

Table 2: analysis of responders by gender

n (%)	Males	Females	Total
Responders	56 (32.0)	119 (68.0)	175
Non-responders	32 (37.6)	53 (62.4)	85
Total	88	172	260

Table 3: mean age by responding

	n	Mean	Std. Deviation
Responders	175	45.9	17.1
Non-responders	85	48.1	21.2

Table 4: analysis of non-responders by reason for not participating in the study

Reasons	n	%
Unreachable	22	25,9
Missed appointment / refused	21	24,7
Other diagnosis / wrong diagnosis	15	17,6
Other reasons	13	15,3
Unable to attend appointment	12	14,1
Deceased	2	2,4
Total	85	100,0

Key	
Unreachable	Moved away from the practice. Wrong address or telephone. Away from home during the study period.
Missed appointment / refused	Had accepted when invited but never attended or refused when invited.
Other diagnosis/ wrong diagnosis	Had wrongly been labelled as having asthma or had another respiratory disease without asthma (COPD).
Other reasons	Not stated.
Unable to attend appointment Deceased	Due to old age, physical condition or being bedridden, Died between randomisation and appointment.

The study population was largely from a working class and middle class background with a mean Graffar score of 16 (sd 3.5). The distribution of the Graffar score by classes can be seen in table 5.

Table 5: Characteristics of the study sample by classes of Graffar score

Class		Score	n	%
Class I	**Upper**	**5-9**	7	4.0
Class II	**Upper middle**	**10-13**	33	18.9
Class III	**Middle**	**14-17**	73	41.7
Class IV	**Lower middle**	**18-21**	52	29.7
Class V	**Lower**	**22-25**	10	5.7
Total			175	100.0

In terms of severity of asthma, most patients had intermittent asthma 42.9%, with mild persistent asthma diagnosed in 24%, moderate persistent asthma in 28.6% and severe persistent asthma in 4.6% (Table 6).

Table 6: Distribution of the patients in the sample by levels of severity of asthma

Severity of asthma	n	%	95% confidence intervals
Intermittent	75	42.9	36.7 to 49.0
Mild persistent	42	24.0	18.7 to 24.3
Moderate persistent	50	28.6	22.9 to 34.2
Severe persistent	8	4.6	1.9 to 7.2
Total	175	100.0	

Details of medication use are given in table 3 and 4. Short acting beta agonists were used as relief medication in 49.7% of the patients. No medication was required by 37% of the patients. The most common controller medication was a combination of an inhaled corticosteroid and a long acting beta agonist, used by 24% of the patients. Inhaled steroids alone were used by 14.9% of the patients. No controller medication was used by 49% of patients.

Table 7: Relief medications used by the patients in the sample

Relief Medication	n	%
Anti-Cholinergics	3	1.7
None	66	37.7
Other	19	10.9
SABA	87	49.7
Total	175	100.0

Table 8: Control medications used by the patients in the sample

Control Medication	n	%
ICS	26	14.9
ICS + LABA	42	24.0
LABA	5	2.9
Leukotriene inhibitors	1	0.6
None	81	46.3
Other	18	10.3
Theophylline	2	1.1
Total	175	100.0

Comorbidities are shown in table 9. Concomitant comorbidity was found in 70% of patients with 48% of patients having only one additional comorbid condition. Coexisting comorbid conditions were found in 50% of patients with 27% having only one additional coexisting condition. Table 10 shows the distribution of the main comorbidities.

Table 9: Number and percentage of patients per number of concomitant and coexisting co-morbid conditions in the sample (n=175)

Number of Concomitant co-morbidities	n	%	Number of Coexisting co-morbidities	n	%
0	54	30.9	0	88	50.3
1	84	48.0	1	47	26.9
2	27	15.4	2	19	10.9
3	6	3.4	3	14	8.0
4	3	1.7	4	5	2.9
5	1	0.6	5	2	1.1
Total	175	100.0	Total	175	100.0

Table 10: frequency of the most common concomitant co-morbid conditions per total number of cases (n=175)

Co-morbidities	n	%
Allergic rhinitis	69	39.4
Obesity	30	17.1
Smoking	25	14.3
Sinusitis	16	9.1
Allergy	8	4.6
COPD	5	2.9

Measurements of lung function included peak expiratory flow (PEF) and forced expiratory volume in 1 second (FEV1). The mean PEF in the study population was 372 (sd 154) with a median of 52 and a range of 75 to 813. The mean PEF was 72.9% of the predicted value (median 75.6%) with values in the range of 18 to 171%.

The mean FEV1 was 2.64 litres (sd 1.09) with a median of 2.57 and a range of 0.53 to 5.91. The mean FEV1 was 92.8% of the predicted (median 92.7%) with the percent predicted ranging from 35% to 233%. In table 11, PEF and FEV1 values and percent of expected values from the sample patients are show.

Table 11: PEF and FEV1 values and as percent of expected values in the sample patients.

	n	Minimum	Maximum	Mean	Std. Deviation
PEF	175	75	813	372.6	154.4
Percent PEF	175	18.9	171.7	72.9	24.5
FEV1	175	0.5	5.9	2.6	1.1
Percent FEV1	175	35.2	233.0	92.8	25.3

With regard to measures of control of asthma, the Asthma Control Test had a mean score of 20.7 (sd 4.7) with a median of 22 and a range of 7 to 25. Asthma was not controlled in 51 patients (29.1%) and was partially or totally controlled in 124 patients (70.9%) (Table 12).

Table 12: Distribution of the patients in the sample by levels of control of asthma

Level of control of asthma	n	%	95% confidence intervals
Controlled	43	25.1	19.8 to 30.5
Partially controlled	81	46.3	40.1 to 52.5
Uncontrolled	51	24.6	19.2 to 29.9
Total	175	100.0	

Patient enablement was measured with the Patient Enablement Instrument with a mean score of 6.5 (sd 3.6) a median of 6 and a range of 0 to 12. A PEI score > 6 was found in 97 patients (55.4%), thus indicating a clinically meaningful enablement (Table 13).

Table 13: Distribution of the patients in the sample by levels of enablement (mPEI)

mPEI score	n	%
Low (≤6)	78	44.6
High (>6)	97	55.4
Total	175	100.0

Asthma quality of life measured by the Mini-AQLQ revealed a mean score of 5.6 (sd 1.3) with a median of 5.87 and a range of 1.07 to 7.0 (Table 14).

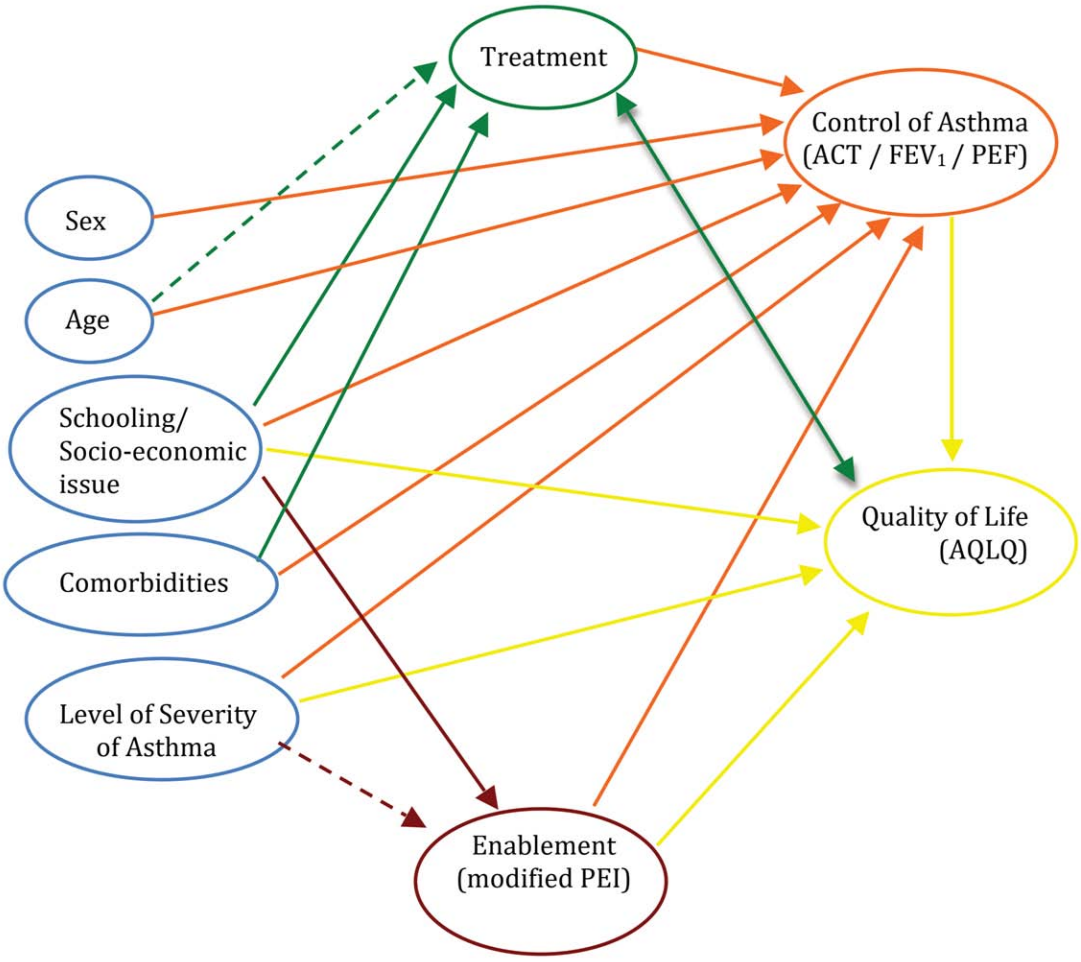
Table 14: Distribution of Mini-AQLQ in the sample patients

	N	Minimum	Maximum	Mean	Std. Deviation
Mini-AQLQ	175	1.1	7.0	5.6	1.3

Bivariate analysis

Bivariate analysis was performed to assess the relationship between variables. The main outcome variables such as severity, asthma control (ACT), quality of life (Mini-AQLQ) and enablement (mPEI) were analysed in relation to the independent variables gender, age, socio-economic status (Graffar), concomitant and coexisting co-morbidities, relief and control Medication and respiratory function measures (PEF and FEV1). Figure 1 shows the relationship between variables that was analysed.

Figure 1: relationship between variables



Severity

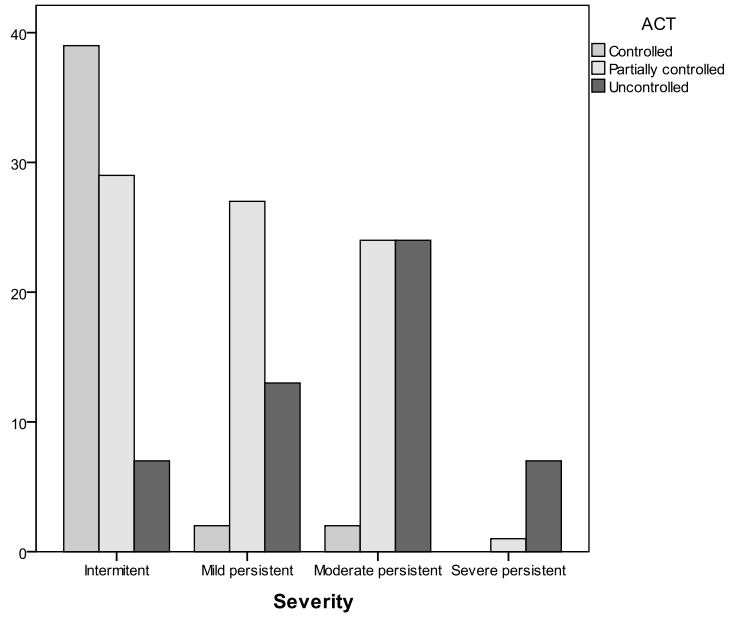
For purposes of analysis, severity was classified with the established scale mentioned in the introduction: intermittent, mild persistent, moderate persistent and severe persistent. In some analyses the two groups of moderate persistent and severe persistent asthma were combined to permit analysis with the chi squared statistic.

Patients with more severe asthma have a lower level of control (Table 15 and Figure 2). This difference is statistically significant ($p<0.001$). The assessment of severity of asthma and control are based on the presence of certain features such as symptoms or the use of medication. The table shows the relationship between the two classifications, though there is an overlapping of criteria contributing to their definition.

Table 15: Control of asthma by levels of severity (n=175)

Level of control	Severity: Intermittent		Mild persistent		Moderate persistent		Severe persistent	
	n	%	n	%	n	%	n	%
Controlled	39	52.0	2	4.8	2	4.0	0	0
Partially controlled	29	38.7	27	64.3	24	48.0	1	12.5
Uncontrolled	7	9.3	13	31.0	24	48.0	7	87.5
Total	75	100.0	42	100.0	50	100.0	8	100

Figure 2: Control of asthma by levels of severity (n=175)

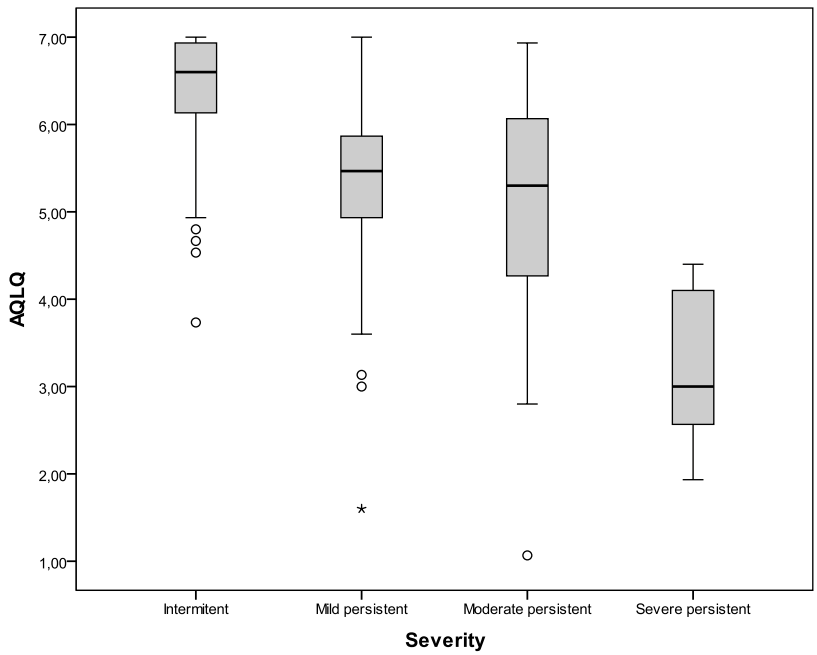


Quality of life (mini-AQLQ score) is inversely proportional to the level of severity (Kruskal Wallis Test, Chi-square=64.257, p<0.001) (Table 16 and Figure 3). There are significant differences in quality of life between intermittent asthma and all the other forms of asthma, between severe persistent asthma and all other forms, but there is no significant difference between mild and moderate persistent asthma in terms of quality of life. Mann-Whitney Wilcoxon (Int-Mild Pers, Z=-5.300, p<0.001, Mild Pers – Mod Pers, Z=-0.878, p>0.05; Mod Pers-Sev Pers, Z=-3.373, p<0.001)

Table 16: Quality of life measured by Mini-AQLQ score by levels of severity (n=175)

	n	Mean	Std. Deviation
Intermittent	75	6. 4	0.7
Mild persistent	42	5.4	1.1
Moderate persistent	50	5.0	1.4
Severe persistent	8	3.3	0.9
Total	175	5.6	1.3

Figure 3: Quality of life measured by Mini-AQLQ by levels of severity of asthma (n=175)



There is a statistically significant difference between the mean percent of predicted PEF and the level of asthma severity (Chi-square=20.19, p<0.001) (Table 17 and Figure 4). There is a statistically significant difference between the mean percent of predicted FEV1 and the level of asthma severity (Chi-square=15.33, p<0.01) (Table18 and Figure 5). Patients with severe persistent asthma have significantly lower percent of predicted PEF and percent of predicted FEV1 compared to patients with other degrees of severity.

Table 17: Mean percent of predicted PEF by level of asthma severity

	n	Mean	Std. Deviation
Intermittent	75	78..2	19.7
Mild persistent	42	73.5	29.4
Moderate persistent	50	70.3	23.4
Severe persistent	8	37.9	13.6
Total	175	72.9	24.5

Figure 4: Mean percent of predicted PEF by level of asthma severity

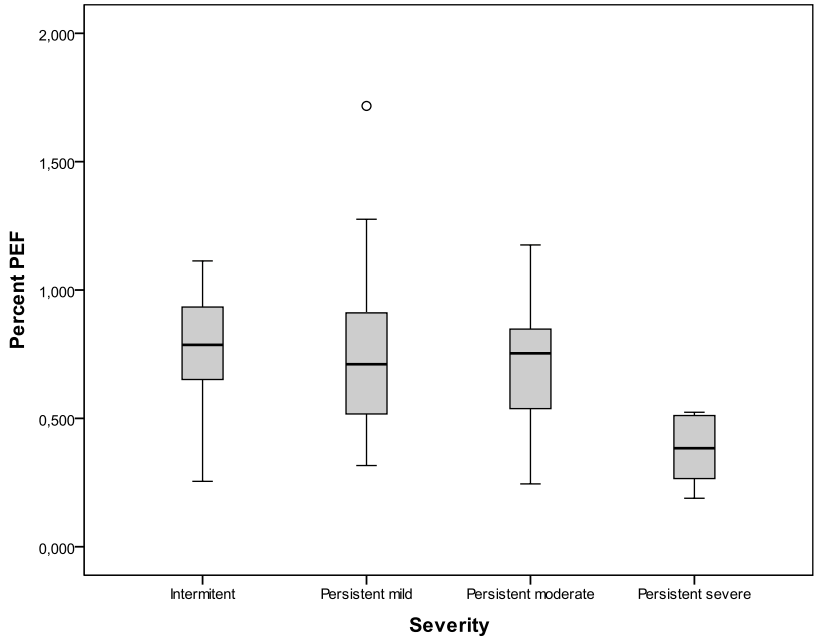
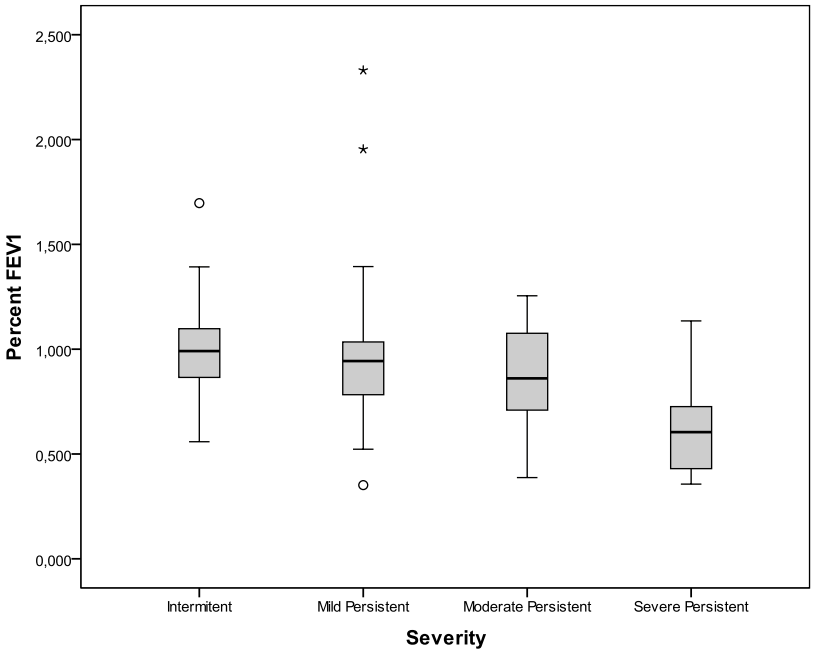


Table 18: Mean percent of predicted FEV1 by level of asthma severity

	n	Mean%	Std. Deviation
Intermittent	75	98.0	18.8
Mild persistent	42	95.9	33.3
Moderate persistent	50	87.2	22.3
Severe persistent	8	62.6	25.1
Total	175	92.8	25.3

Figure 5: Mean percent of predicted FEV1 by level of asthma severity

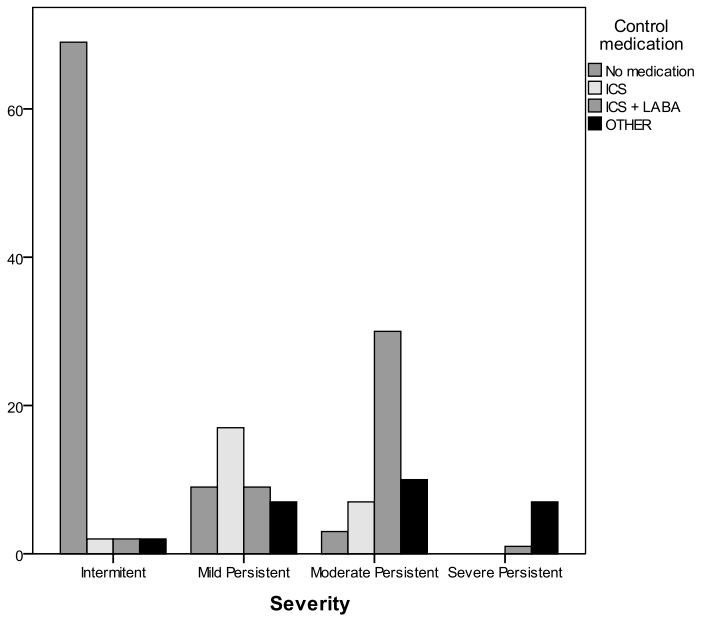


The distribution of patients between Severity and Control medication was not independent (Chi square=166.65, p>0.05). This means that patients with more severe asthma use more control medication (87.5%) when compared with patients with intermittent asthma (92.0% without medication). (Table 19, Figure 6).

Table 19: Severity by type of control medication

	Control medication				
Severity n (%)	No medication	ICS	ICS + LABA	OTHER	Total
Intermittent	69 (92.0)	2 (2.7)	2 (2.7)	2 (2.7)	75 (100.0)
Mild Persistent	9 (21.4)	17 (40.5)	9 (21.4)	7 (16.7)	42 (100.0)
Moderate Persistent	3 (6.0)	7 (14.0)	30 (60.0)	10 (20.0)	50 (100.0)
Severe Persistent	0 (0.0)	0 (0.0)	1 (12.5)	7 (87.5)	8 (100.0)
Total	81 (46.3)	26 (14.9)	42 (24.0)	26 (14.9)	175 (100.0)

Figure 6: Severity by type of control medication



Severity of asthma is independent of gender, social economic status (Graffar), and the number of concomitant and coexisting co-morbidities.

The analysis of variance showed that there was a significant difference between the mean age of the patients by severity using three classes ($F=4.810$, $p<0.001$) (Table 20). Patients in the severe and moderate persistent group were older than patients in the intermittent group (Tukey HSD).

Table 20: ANOVA age by severity

Level of severity	n	Mean age	Std. Deviation
Intermittent	75	41.4	15.9
Mild Persistent	42	48.3	17.4
Moderate + Severe Persistent	58	50.0	17.4
Total	175	45.9	17.1

Asthma Control (ACT)

The analysis of the level of control using the Asthma Control Test ACT was performed using three categories: controlled, partially controlled and uncontrolled, (for cut-off values of the ACT scores of 25, 20-24 and ≤ 19 respectively) or two categories: goo d control and poor control, (for cut-off values of 20-25 and ≤ 19 respectively). Analysis was done using the two methods,

Males have higher ACT scores than females (Chi square= 8.803, p<0.01) (Table 21). Table 22 and Figure 7 show the mean age of patients in the three control classes.

Table 21: Analysis of levels of control of asthma by gender (n=175)

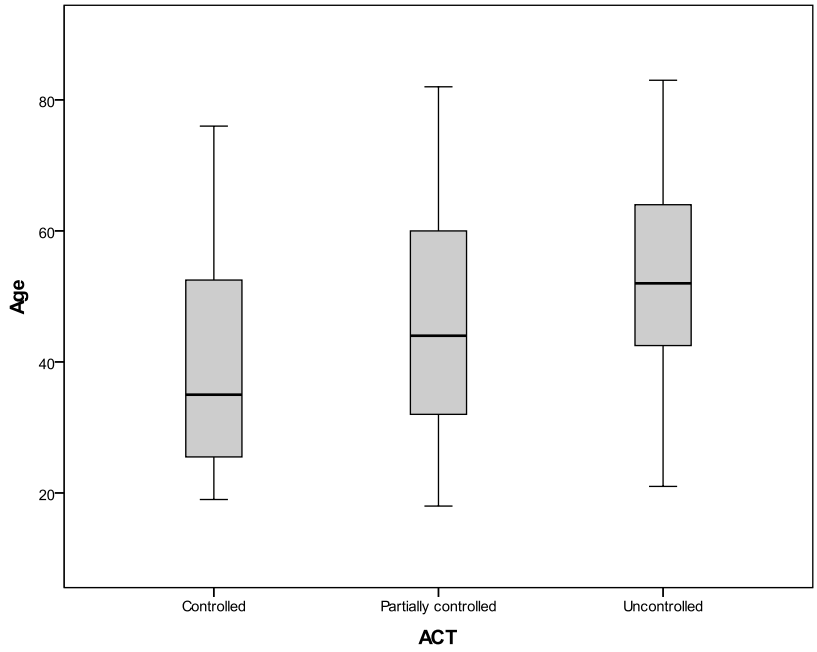
Gender n (%)	ACT Good Control	Poor Control	Total
Male	48 (85%)	8 (15%)	56
Female	76 (64%)	43 (36%)	119
Total	124 (71%)	51 (29%)	175

Patients with a better control of asthma are younger (F=6.775, p<0.005). Post hoc tests (Tukey HSD) showed that age was significantly different between uncontrolled and controlled asthma.

Table 22: Mean age by levels of control of asthma (three classes)

Asthma control	n	Mean age	Std. Deviation
Controlled	43	38.9	16.1
Partially controlled	81	46.1	16.9
Uncontrolled	51	51.5	16.5
Total	175	45.9	17.1

Figure 7: Age by levels of control (n=175)



When we consider the levels of control in two catergories, there is a significant difference between the mean age of patients with good and poor control of asthma (t=2.837, p<0.01) (table 23) with older patients having poorer asthma control.

Table 23: Mean age by levels of control of asthma (two classes)

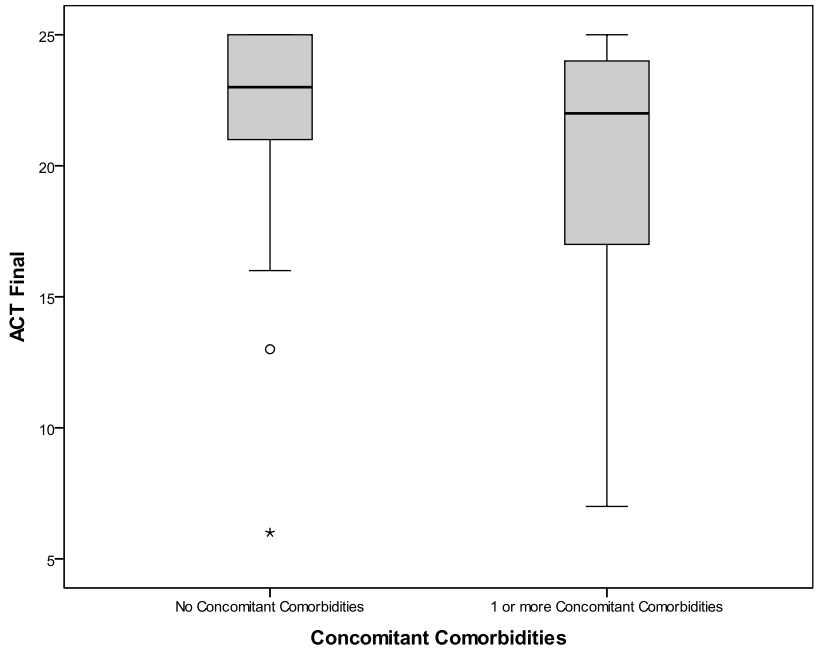
Asthma Control (ACT)	n	Mean Age	Std. Deviation
Good Control	124	43.6	16.9
Poor Control	51	51.5	16.5

As can be observed in table 24 and figure 8 the distribution of patients with concomitant co-morbidities is not independent of the levels of control of asthma (Chi square=12.06, p< 0.05). Patients with more co-morbidities have a lower level of control. In patients with uncontrolled asthma, 86.3% have at least one co-morbidity.

Table 24: distribution of patients with concomitant co-morbidities by levels of control of asthma (ACT)

	Concomitant co-morbidity			
Asthma Control ACT n (%)	No co-morbidity	1 co-morbid condition	2 or more co-morbid conditions	Total
Controlled	16 (37.2)	16 (37.2)	11 (25.6)	43 (100.0)
Partially Controlled	31 (38.3)	38 (46.9)	12 (14.8)	81 (100.0)
Uncontrolled	7 (13.7)	30 (58.8)	14 (27.5)	51 (100.0)
Total	54 (30.9)	84 (48.0)	37 (21.1)	175 (100.0)

Figure 8: distribution of patients with concomitant co-morbidities by levels of control of asthma (ACT)



Most patients without control medication are either controlled or partially controlled. Patients with more medication are more likely to be found in the partially controlled and uncontrolled groups. This difference in the distribution is statistically significant (Chi square=48.64, p< 0.05) (Table 25).

Table 25: levels of control of asthma (ACT) vs control medication

	Control medication				
Asthma Control ACT n (%)	**No medication**	**ICS**	**ICS + LABA**	**OTHER**	**Total**
Controlled	38 (88.4)	2 (4.7)	2 (4.7)	1 (2.3)	43 (100.0)
Partially Controlled	34 (42.0)	13 (16.0)	22 (27.2)	12 (14.8)	81 (100.0)
Uncontrolled	9 (17.6)	11 (21.6)	18 (35.3)	13 (25.5)	51 (100.0)
Total	81 (46.3)	26 (14.9)	42 (24.0)	26 (14.9)	175 (100.0)

Most patients without relief medication are either controlled or partially controlled. There are more patients in the partially controlled or uncontrolled groups using relief medication (Chi square=22.43, p< 0.001) (Table 26).

Table 26: levels of control of asthma (ACT) vs relief medication

	Relief medication			
Asthma Control ACT n (%)	No medication	SABA	All Other	Total
Controlled	28 (65.1)	13 (30.2)	2 (4.7)	43 (100.0)
Partially Controlled	27 (33.3)	45 (55.6)	9 (11.1)	81 (100.0)
Uncontrolled	11 (21.6)	29 (56.9)	11 (21.6)	51 (100.0)
Total	66 (37.7)	87 (49.7)	22 (12.6)	175 (100.0)

Asthma control (ACT) is independent from socioeconomic status (Graffar).

The analysis of variance showed that there was a significant difference between the mean percent of predicted PEF of the patients by level of asthma control (F=6.963. p<0.001) (Table 27). The mean percent of predicted PEF of the uncontrolled group was statistically different from the other groups. (Tukey HSD).

Table 27: Asthma control (ACT) vs percent of predicted PEF

		Percent predicted PEF	
Asthma control ACT	n	Mean %	Std. Deviation
Controlled	43	78.7	20.3
Partially Controlled	81	76.4	25.0
Uncontrolled	51	62.6	24.2
Total	175	72.9	24.5

The analysis of variance showed that there was a significant difference between the mean percent of predicted FEV1 of the patients by level of asthma control (F=7.299. p<0.001) (Table 28). The mean percent of predicted FEV1of the uncontrolled group was statistically different from the other groups. (Tukey HSD).

Table 28: Asthma control (ACT) vs percent of predicted FEV1

		Percent predicted FEV1	
Asthma control ACT	n	Mean %	Std. Deviation
Controlled	43	97.4	18.6
Partially Controlled	81	97.3	26.6
Uncontrolled	51	81.8	25.2
Total	175	92.8	25.3

When we consider the relationship between asthma control and the number of concomitant co-morbidities, there is a significant difference between the mean ACT in patients without co-morbidities and those having one or more (t=3.256, p<0.01) (table 29).

Table 29: asthma control (ACT) vs number of concomitant co-morbidities

Number of co-morbidities	n	Mean ACT score	Std. Deviation
No Concomitant co-morbidities	54	22.2	3.5
1 or more Concomitant co-morbidities	121	20.1	5.1

Patient Enablement

The level of patient enablement was measured using the modified Patient Enablement Instrument (mPEI). The established cut-off value for mPEI is 6, a value ≤6 meaning a Low Enablement and >6 a High Enablement.

Bivariate analysis was performed to assess the association between mPEI and other measures of asthma control. No significant association was found between the mPEI score and the Mini-AQLQ score, the ACT score, the level of %FEV1, %PEF or asthma severity using ANOVA.

The correlation between enablement (mPEI) and age was low (Figure 9) but when mPEI is studied in two classes, there is a significant difference between the mean age of patients with low and high levels of enablement (t=3.901. p<0.001) (Table 30 and Figure 10). There is a significant difference between the mean mPEI score in males and females (t=1.986. p<0.05) (Table 31 and Figure 11).

Figure 9: correlation between enablement (mPEI) and age

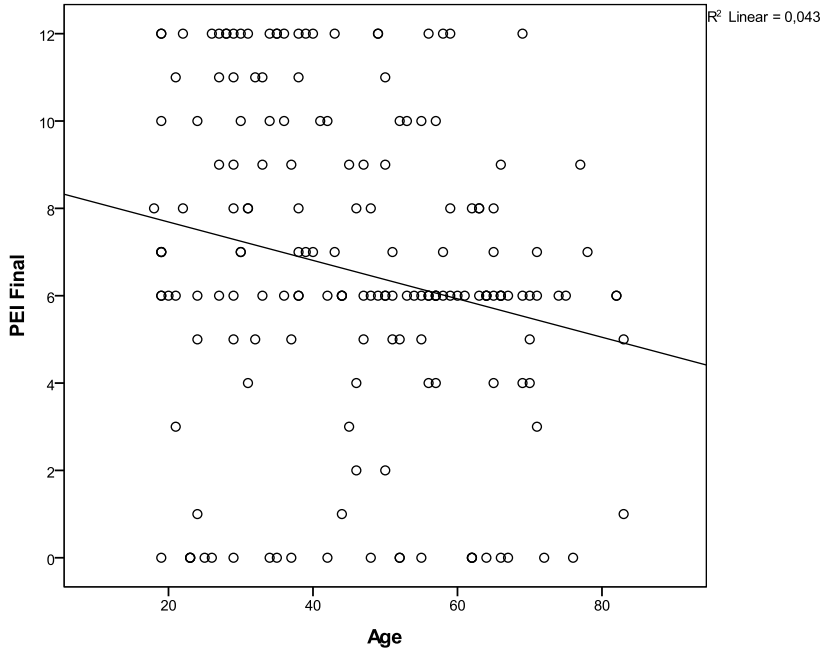


Table 30: Mean age by levels of enablement

PEI	n	Mean age	Std. Deviation
Low	78	40.5	15.3
High	97	50.3	17.4
Total	175	45.9	17.1

Figure 10: Mean age by levels of enablement

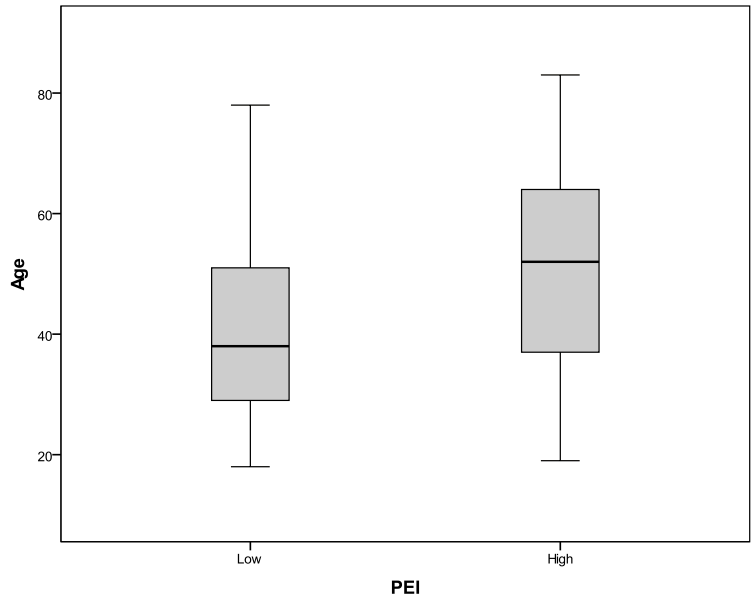
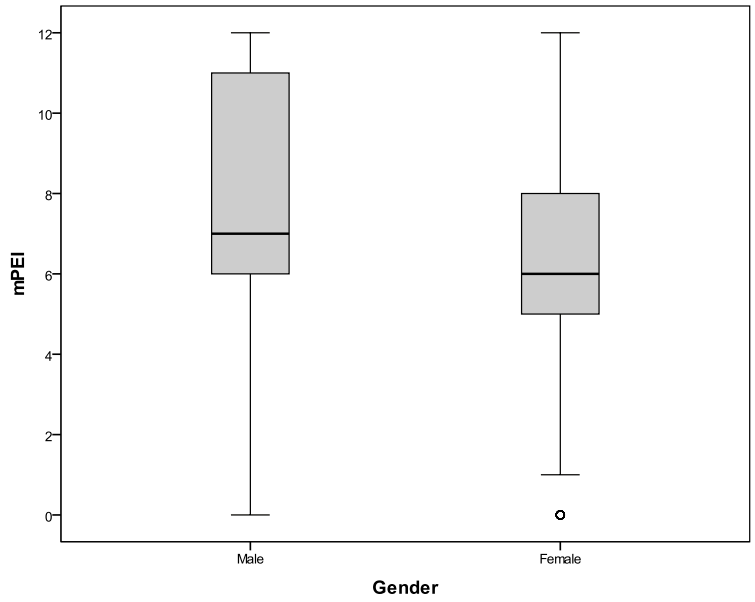


Table 31: Mean mPEI score by gender

Gender	n	Mean PEI score	Std. Deviation
Male	56	7.34	3.9
Female	119	6.18	3.5

Figure 11: Mean mPEI score by gender



There is no statistically significant difference between the mean mPEI score and the level of asthma severity - Kruskal Wallis Test (Chi-square=1.98057. p>0.05) (Table 32).

Table 32: Mean mPEI score by level of asthma severity

		mPEI	
Asthma control ACT	**n**	**Mean score**	**Std. Deviation**
Intermittent	75	6.1	4.5
Mild Persistent	42	7.3	2.5
Moderate Persistent	50	6.8	3.1
Severe Persistent	8	5.4	1.9
Total	175	6.5	3.6

The mPEI score is lower with lower socio-economic status, though this was not found to be statistically significant association.

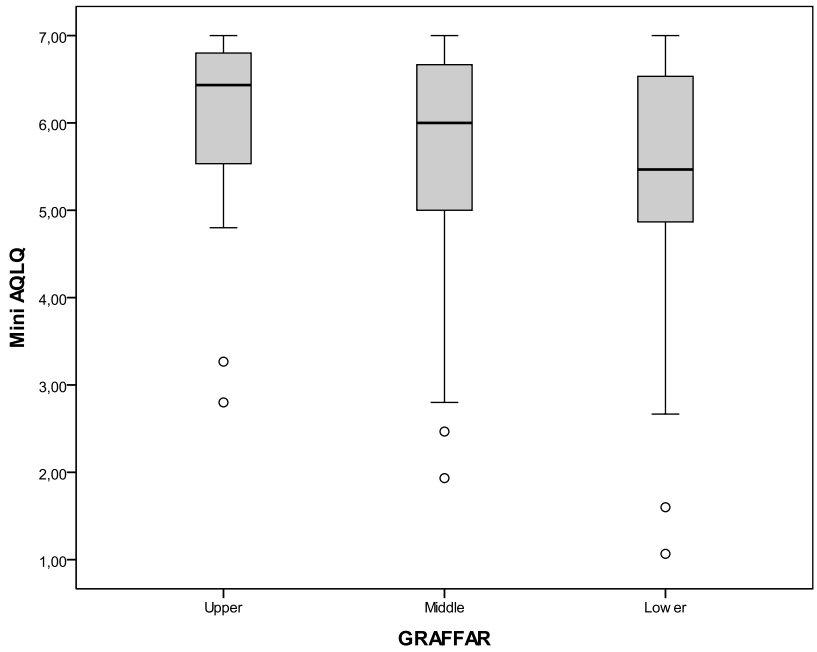
Quality of Life

The analysis of variance of the relationship between quality of life (mini-AQLQ) and socio-economic status (Graffar) revealed that there is a statistically significant difference (F=4.07. p> 0.05). Post hoc tests (Tukey HSD) showed that mini-AQLQ was significantly different between the upper and lower social groups (Table 33) (Figure 12).

Table 33: Relationship between quality of life (mini Mini-AQLQ) and socio-economic status (Graffar)

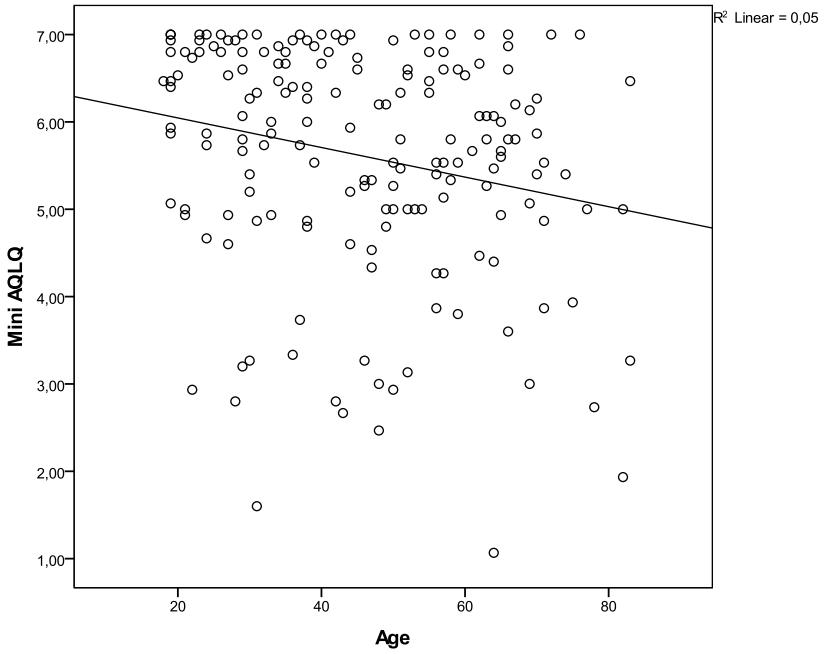
Graffar class	n	Mean AQLQ score	Std. Deviation
Upper	40	6.0	1.0
Middle	73	5.6	1.3
Lower	62	5.3	1.4
Total	175	5.6	1.3

Figure 12: Relationship between quality of life (mini-AQLQ) and socio-economic status (Graffar)



The correlation between quality of life (Mini-AQLQ) and age was weak (Figure 13).

Figure 13: Correlation between quality of life (Mini-AQLQ) and age



There is a significant difference of the Mini-AQLQ score (quality of life) by gender (t=5.54. p<0.001) (Table 34).

Table 34: Mini-AQLQ score (quality of life) by gender

Gender	n	Mean AQLQ score	Std. Deviation
Male	56	6.2	0.8
Female	119	5.3	1.4

The correlation between quality of life (Mini-AQLQ) and concomitant and coexisting co-morbidities, percent of PEF and percent of FEV1 was low.

Bivariate analysis of the relationship between outcome variables

There was a strong and statistically significant correlation in this population between the scores on the ACT and the MINI-AQLQ (r=0.81. p<0.001). However, the correlations between mPEI and ACT and mPEI and MINI-AQLQ were weak. The scatter plots of these variables are given in figures 14, 15 and 16.

Figure 14: relationship between asthma control test (ACT) scores and quality of life questionnaire (mini-AQLQ) scores in the EQLAP study (n=175)

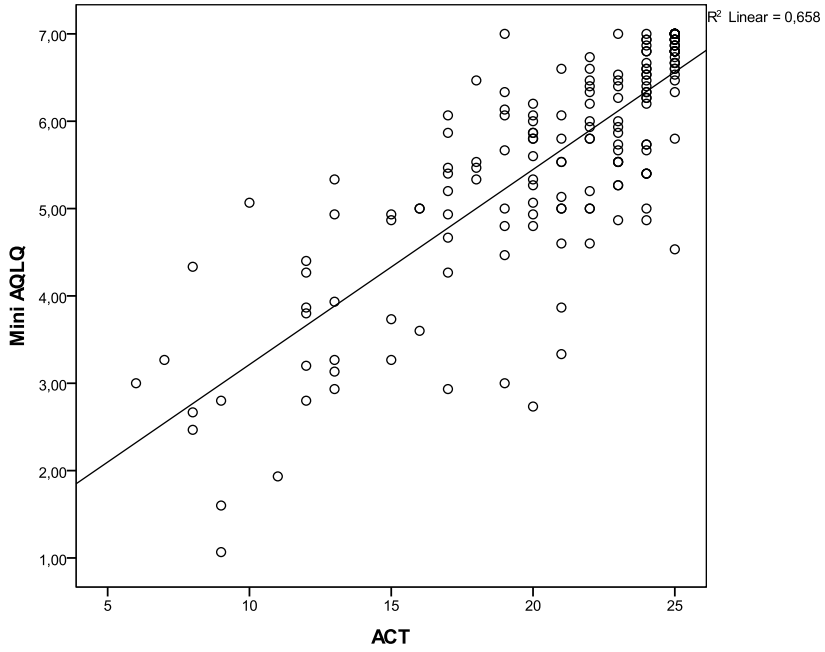


Figure 15: relationship between asthma control test (ACT) scores and mPEI scores in the EQLAP study (n=175)

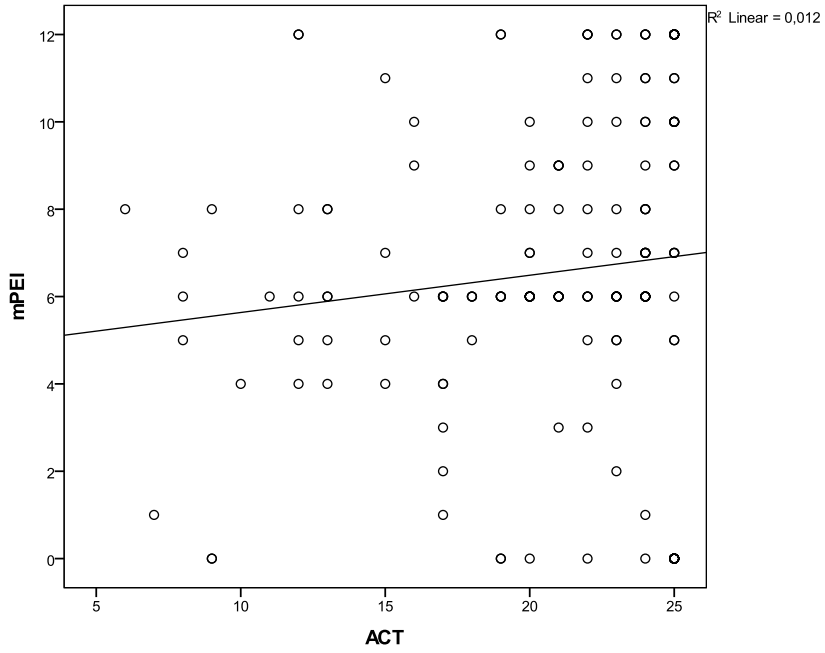
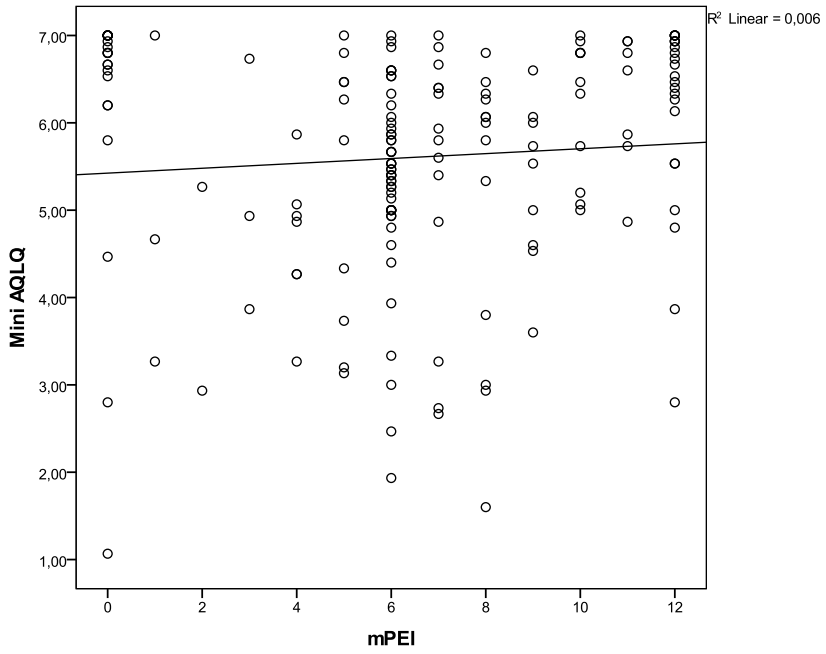


Figure 16: relationship between quality of life (mini-AQLQ) scores and mPEI scores in the EQLAP study (n=175)



The instrument used in the present study to measure asthma control was the Asthma Control Test. (ACT). The analysis of the level of control using ACT can be done using two or three categories. For the following analysis, two categories with a cut-off value of 20 (Good control = 20-25 and Poor control ≤ 19) was used.

In order to establish a cut-off value for the quality of life measurement using the mini-AQLQ, a ROC (Receiver Operating Curve) analysis was performed. Patients were classified in two groups (controlled and uncontrolled) according to ACT. Using this cut-off, the distribution of Mini-AQLQ scores for the two groups was studied. Assuming that better control is related to a better quality of life, the ROC (Receiver Operating Characteristic Curve) analysis [41] provides the Mini-AQLQ cut-off that minimizes the misclassification of patients as controlled or uncontrolled as a function good and poor quality of life (Mini-AQLQ) (Figure 17). The cut-off value was fixed for a specificity and sensitivity of 80%. This analysis suggests that a Mini-AQLQ score less than 5.4 is related to a worse asthma control and lower quality of life and a score greater or equal to 5.4 is related to a better control and higher quality of life (Figure 18). Area Under the Curve AUC= 0.878, 95%CI [0.821, 0.935])

Figure 17: ROC curve of mini-AQLQ vs ACT

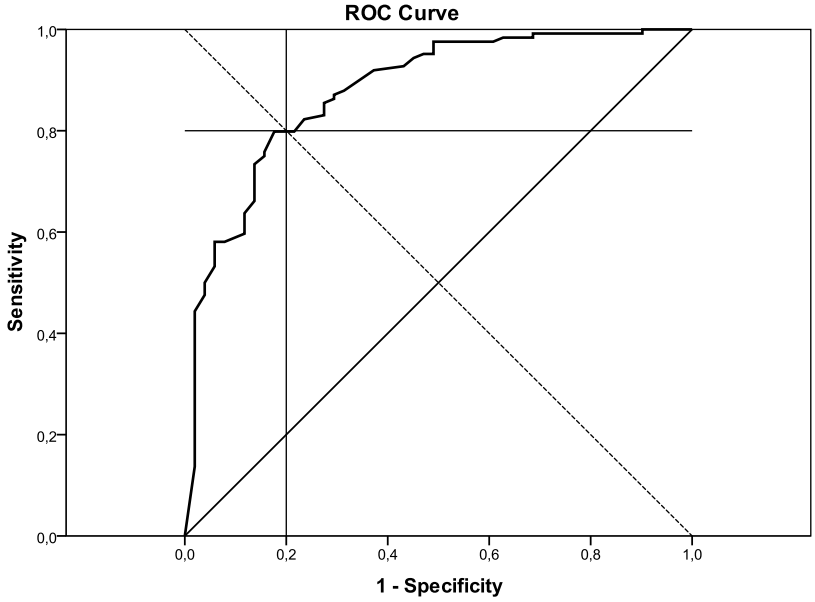
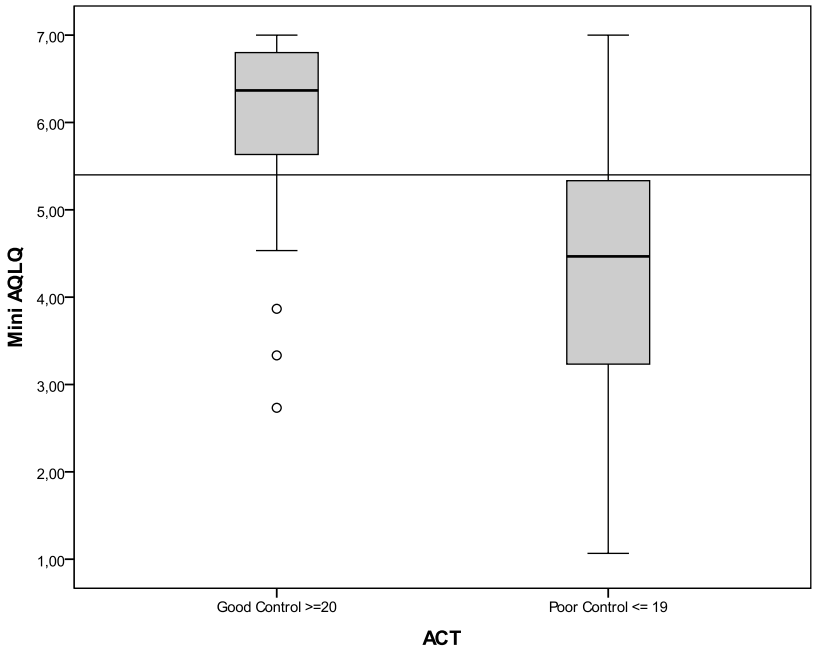


Figure 18: mini-AQLQ vs ACT



Logistic regression model

Logistic regression models were constructed to assess the association between demographic and other predictor variables and asthma control (ACT) and quality of life (mini AQLQ) as outcome variables using a backward conditional method. The choice of the variables in the model was based on the bivariate analysis. The variables asthma control (ACT) and quality of life (mini AQLQ) were categorized in two levels: less than 20 for ACT and less than 5.40 for mini AQLQ.

The model coefficients for ACT are presented in table 8. The variables gender, socio economic status (Graffar), the number of concomitant co-morbidities, control medication, severity, enablement (mPEI), %PEF, %FEV1, age and relief medication were entered into the model.

Model fit was assessed by the likelihood ratio statistic (Chi-square=61.220, d.f.=7, $p<0.001$) and by the Hosmer and Lemeshow test (Chi-square=6.047, d.f. = 8, $p = 0.642$). The logistic coefficients for all the variables are positive, indicating an increase in the log odds of being in poor asthma control. These values can be interpreted in terms of the odds ratio (OR), assuming that all other variables are held constant.

Female gender is associated with poor control (OR=3.2). Severity is associated with poor control, with the more severe stages showing greater OR values (4.2 and 9.5, respectively, considering intermittent asthma as the reference class). A value of FEV1 below 80% of the expected value is associated with poor control (OR=3.4). The analysis of concomitant comorbidities also shows that a higher number of comorbidities is related to a lower control (OR values of 4.2 and 5.6, respectively). Patient enablement (mPEI) appears to indicate that lower enablement is associated with poor control (Table 35) but this finding was not statistically significant (p=0.53).

Table 35: Logistic regression model for asthma control (ACT). Variables in the equation

							95% C.I. for EXP(B)	
	B	**S.E.**	**Wald**	**df**	**Sig.**	**EXP(B)**	**Lower**	**Upper**
Gender	1.2	0.5	5.3	1	**0.022**	**3.2**	1.2	8.8
Concomitant co-morbidities			8.5	2	0.014			
1 concomitant co-morbidity	1.4	0.5	6.5	1	**0.011**	**4.2**	1.4	12.4
2 or more concomitant co-morbidities	1.7	0.6	7.3	1	**0.007**	**5.6**	1.6	19.5
FEV1 < 80%	1.2	0.5	7.1	1	**0.008**	**3.4**	1.4	8.3
Low mPEI	0.8	0.4	3.7	1	0.053	**2.3**	0.9	5.2
Severity			17.8	2	0.000			
Moderate Persistent Asthma	1.4	0.6	6.4	1	**0.011**	**4.3**	1.4	12.6
Severe Persistent Asthma	2.2	0.5	17.8	1	**0.000**	**9.5**	3.3	26.9
Constant	-6.3	1.2	26.6	1	0.000	0.002		

The model coefficients for Mini-AQLQ are presented in table 36. The variables gender, socio-economic status (Graffar), severity and enablement (mPEI) were entered into the model.

Model fit was assessed by the likelihood ratio statistic (Chi-square=49.917, d.f.=5, p<0.001) and by the Hosmer and Lemeshow test (Chi-square=3.980, d.f = 8, p=0.859).

The logistic coefficients for all the variables are positive, indicating an increase in the log odds of being in poor asthma control.

Female gender was associated with a worse quality of life (OR=3.8). Patients with moderate persistent and severe persistent asthma have a worse quality of life compared to patients with the reference condition, intermittent asthma (OR values of 6.9 and 9.1, respectively). A low enablement (mPEI) appears to be associated with poor quality of life but this finding was not statistically significant (p=0.057, Table 36).

Table 36: Logistic regression model for quality of life (mini AQLQ). Variables in the equation

							95% C.I. for EXP(B)	
	B	**S.E.**	**Wald**	**df**	**Sig.**	**EXP(B)**	**Lower**	**Upper**
Gender	1.3	0.4	9.5	1	**0.002**	**3.8**	1.6	8.8
Severity			26.1	2	0.000			
Moderate Persistent Asthma	1.9	0.5	16.1	1	**0.000**	**6.9**	2.7	17.7
Severe Persistent Asthma	2.2	0.4	23.9	1	**0.000**	**9.1**	3.8	22.1
Low mPEI	0.7	0.4	3.6	1	0.057	**2.0**	0.9	4.2
Constant	-4.6	0.9	25.8	1	0.000	0.010		

Discussion:

The current study found a strong association between asthma control and quality of life in a random sample of asthmatic patients cared for in general practice by seven general practitioners. A weak positive correlation was found between patient enablement and asthma control.

Study questionnaire and diagnostic criteria

The sample size was calculated in order to allow an adequate analysis of the study variables. The results show that the sample size was adequate. The response rate was very high 97.2%, but 45 (25%) patients had to be replaced because they where impossible to reach, where away from their household during the study period, or where not willing to participate. An analysis of the non-responders by age and gender revealed that they were not significantly different from the responders so a response bias is unlikely. The analysis of the reasons for not participating does not show a probable bias, but this has to be considered as possible.

As explained in the description of the methods, exclusion criteria were applied to patients with conditions that could influence the outcome variables or anyone unable to answer the questionnaire or perform respiratory tests because of cognitive impairment or illiteracy.

The assessment of severity of asthma was based on the GINA Report update from 2008. The GINA classification of severity has a number of limitations. According to the GINA guidelines, before treatment is initiated, asthma severity classification is based solely on clinical features. When patients are already receiving medication the classification of severity should be based on the clinical features present and the daily medication regimen. That was one of the reasons for GINA to move from a severity-based to a control-based classification in 2006. [42] In the revised GINA guidelines, severity classification is regarded as suitable only for classification of patients who are

not on treatment. Though it is still controversial whether any classification system can be used to classify asthma severity reliably in patients receiving drug treatment, [43, 44] using this approach it was possible to estimate the level of severity of the patients in the survey by matching the medication in use with the level of severity. Severity was classified this way in the present study. Considering that some patients might need to step-up or down treatment thus being classified at a higher or lower level, this might be a source of bias on the severity classification in the results.

Though the modified Patient Enablement Instrument used in the survey was designed for self-administration, among patients with low literacy, help was required from the researchers in order to complete the form. If the researchers interpreted or explained the questions differently to different patients, this might be a possible source of inter-observer bias.

Most of the study instruments used here have good support in the published literature. However the validation of Portuguese version of the Asthma Control Test has not been published in a peer-review journal. There is a validated version published in Portuguese from Brazil [45] which uses a slightly different phrasing than the version in use in Portugal. [46] Several papers have used this version [47-50] and its clinical use is common both in secondary and primary health care so its use was considered trustworthy for this study.

The Asthma Quality of Life Questionnaire (AQLQ) [21] has been translated and validated for the Portuguese population. [22, 23]

A possible source of measurement bias is the skill required from patients to measure FEV1 and PEF. To reduce this effect, the researchers have used standardized instructions for patients as mentioned in the methods section.

To analyse respiratory function the FEV1 and PEF values were entered in a database and the percentage was calculated against the expected values for gender, age and height.

Comparison of findings with other published studies

Severity of asthma and medication use

In our survey, the study sample was obtained from a database of patients with doctor-diagnosed asthma. All asthma patients were eligible to participate, whether they had intermittent or more severe forms of asthma. This may explain the difference in distribution by severity levels observed in the sample population compared to other studies. [51, 52] One survey used a different age range (15-45 years) with patients from a data base of primary health care centres employing a specialized asthma clinic which might only treat the more severe cases. [53] Another study used a large population from ten centres in eight countries. In that study an additional category of severity, asthma in remission, was used. [54] A Spanish survey from primary health care found a similar distribution of asthma severity as our study. [55]

Few recent studies were found describing the use of asthma medication in primary care patients. Most studies used a different classification of medication, making comparisons with the present survey difficult.

Asthma control and quality of life

The level of severity of asthma and the level of control are two correlated measures, but both concepts are important and conceptually distinct. In the study by Vollmer et al, the authors demonstrate that asthma control correlates strongly with both generic and disease-specific indices of quality of life. [56]

The frequency of controlled and uncontrolled asthma described in the present study was found to be similar to the one achieved in an outpatient clinic from an allergology department in a central hospital in Portugal. [49] Though this represents a good outcome, we have to consider that patients with different levels of severity of asthma are being cared for in the two services and the age range was different.

A Swedish survey by Ställberg et al., showed a similar level of uncontrolled asthma as the present study, though with a smaller number of partially controlled patients. [57]

The existing literature has demonstrated a good relationship between asthma control and quality of life. [24, 25] The inclusion of patient-centred measures in monitoring asthma is important for guiding clinical management, predicting health outcomes, formulating clinical policy and assisting in the allocation of resources. [24]

In a survey by Schatz et al., the authors used the ACT and the Mini-AQLQ to study the relationship between asthma-specific quality of life and asthma control and found that asthma control tools reflect the symptom and activity limitation aspects of quality of life. The control tools correlate well with emotional aspects but significantly less well than symptom or activity measures. [58] In the study by Lobo et al., asthma control measured by the Asthma Control Questionnaire is negatively correlated with all the quality of life variables. [59]

Wijnhoven et al. report that the presence of co-morbid conditions is also associated with poor disease-specific health-related quality of life in asthma. [60] In their survey, in 25 general practices in three regions of the Netherlands, the authors report on the frequency of co-morbidities and assess the association between somatic co-morbidity and both disease-specific and general HRQoL in asthma and COPD patients aged 40-75 years. The proportion of co-morbidities is not comparable to the ones in the EQLAP study, as a different classification was used.

Enablement, asthma control and quality of life

Evidence for the value of assessment of patient enablement in asthma is lacking. A few studies have shown that training patients in self-assessment through the use of a peak flow meter and the recording of symptoms together with regular consultations with health professionals and a written action plan can improve the results of treatment in adults with asthma. [5, 6, 15]

Some authors found a good relationship between different features of patient enablement and good control of asthma. [15] A study by Thoonen et al. shows that most patients are interested in self-management plans. [61] This is not always the case. According to guidelines, inhaler technique should be tested in all patients, particularly those with poorly controlled asthma. However Hardwell et al. showed that despite training, a significant majority of symptomatic asthma patients in this study population were unable to use their prescribed pMDIs correctly. [62]

Warsi A, et al. performed a systematic review and methodological critique of the literature and found that self-management education programs resulted in small to moderate effects for selected chronic diseases. [63]

Doctors are poor at predicting patient satisfaction in the consultation. It is likely that satisfied patients are more likely to comply with treatment. It is important therefore that doctors develop ways of recognizing dissatisfaction during the consultation so that they may identify and address patients concerns. [64]

Findings from a Dutch study by Thoonen et al., indicate that asthma control improved in patients treated by self-management when compared with individuals under usual care with an increase in the number of successfully treated weeks and fewer days of limited activity. [65]

A study by Lavoie et al., found that lower levels of asthma self-efficacy defined as the patient's confidence in their ability to avoid asthma exacerbations when exposed to a variety of triggering situations, were associated with worse asthma control and asthma quality of life. [66]

The existing asthma guidelines recommend the involvement of patients through flexible self-management plans, as often as possible. Allowing the patients the opportunity to improve their knowledge and understanding of asthma can improve trust in their treatment, leading to better adherence to the therapeutic plan. [26]

Patients are interested in using written action plans. When supported by adequate training they can help patients to attain a better control of asthma. [27]

In a study from 2007, Haughney et al. describe a low correlation between the mPEI and the Mini-AQLQ but found a significant correlation between modified PEI total score and change in Mini Asthma Quality of Life Questionnaire. [29] These findings suggest that the mPEI is responsive to a change in a patient's quality of life.

Implications

The findings of the current study suggest that patient enablement is associated with better asthma control and as such should be considered by clinicians as an additional tool in achieving clinical aims in asthma management. Further research is needed to determine if efforts to improve patient enablement result in improvements in asthma control and quality of life. The mPEI or similar instruments may be useful in future research in this area and may have application in routine clinical work as well.

Conclusions

Patients registered with Family Physicians from Matosinhos achieved a good level of asthma control. Asthma was partially or totally controlled in 70.9% patients.

A cut-off value for the score of the quality of life measurement using the Mini-AQLQ was established at 5.4.

The results show a mean score of the mPEI of 6.5, thus indicating a clinically meaningful “enablement”.

Patient enablement was found to be weakly associated with asthma control and quality of life in a population of asthmatics treated in primary care. There was a strong correlation found in this population between asthma control and quality of life. Physicians and patients may benefit from efforts to improve patient enablement in order to improve asthma care.

This study showed that gender, concomintant co-morbidities, FEV1 and severity have a strong causal link with asthma control. With regard to quality of life, gender and severity are the main causal variables.

The results show a mean score of the mPEI of 6.5, thus indicating a clinically meaningful enablement, although there was not a strong causal relation with asthma control and quality of life.

Authors’ contributions

JCS conceived the idea for the study, designed it, collected data, performed data analysis and wrote parts of the introduction, methods, results and discussion sections of the manuscript. AP, AMG, AQ, FAL and JC participated in the design, collected data and contributed to the writing of the methods and results section. PO performed data analysis and wrote parts of the methods results and discussion. JY performed data analysis and wrote parts of the introduction, methods results and discussion. All authors read and approved the final version of the manuscript.

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Conflict of interest and funding

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Discussion

Discussion

The present thesis was developed through three complementary surveys dealing with asthma incidence and prevalence, the variety of shapes and the different levels of severity of asthma in a clinical setting, together with characteristics from patients, including the level of enablement. The thread connecting the three studies was the understanding of how the burden of disease in the general population affects our capacity as clinicians to provide a good level of asthma control and offer a better quality of life to the patients in our care.

Major findings

The main findings of the surveys are:

1. The annual incidence of asthma in the general population in Portugal was 2.02 cases/1000/ year.
2. The accuracy of the diagnosis by family physicians was 83.9%, using accepted diagnostic criteria.
3. The use of the best knowledge about asthma from both the patient and the physician revealed to be a good strategy for the determination of the prevalence of asthma in a community survey.
4. The prevalence of asthma by gender and stratified age groups the urban community studied was 10.24% using data collected from a random sample of the registered population.
5. There was a statistically significant association between the presence of asthma symptoms and a final diagnosis of asthma for wheezing after exercise (OR 4.2), waking up from wheezing (OR 3.4), a personal history of asthma (OR 12), being told by a doctor that the patient has asthma (OR 14.6), use of a short-acting beta agonist in last 12 months, (OR 35.6), use of a long-acting beta agonist in last 12 months (OR 7.6), and the use of an inhaled steroid in last 12 months (OR 25).
6. In a random sample of patients with asthma, most patients had intermittent asthma 42.9%, with mild persistent asthma diagnosed in 24%, moderate persistent asthma in 28.6% and severe persistent asthma in 4.6%.
7. In the studied population, asthma was partially or totally controlled in 70.9% and not controlled in 29.1% patients.

8. There was a strong and statistically significant correlation ($r=0.81$; $p<0.001$) in the population studied between asthma control (measured through the ACT) and quality of life (measured with the Mini-AQLQ).
9. It was possible to establish a cut-off value for the quality of life measurement using the Mini-AQLQ, performing a ROC (Receiver Operating Curve) analysis. This analysis suggests that a mini AQLQ score <5.4 is related to a worse asthma control and lower quality of life and a score ≥5.4 is related to a better control and higher quality of life.
10. It was possible to estimate the different degrees of enablement in the patient sample. The results showed a mean score of the mPEI of 6.5 (sd 3.6). A mPEI score ≥ 6 was found in 127 patients (72.8%), thus indicating a clinically meaningful enablement.
11. From the results in the studies it was not possible to determine the factors that influence the level of enablement of patients with asthma due to probable bias and the sensitivity and specificity of the tool (mPEI).
12. It was not possible to estimate the impact of enablement on morbidity in the patient sample.

Internal validity

The internal validity and main limitations of the studies have been discussed in the appropriate section in each paper. In the next section they are discussed in greater detail.

Asthma incidence studies are not frequent in the literature, as the estimation of the incidence of asthma presents some methodological problems.[81] These relate to the clinical awareness needed to identify the disease in a given patient. In epidemiological incidence studies in which the disease is easily diagnosed as it is marked by a major event, such as stroke or hip fracture, the time of diagnosis is easily established. For chronic diseases starting in an insidious, slow or progressive way, such as asthma, it is often difficult to establish when the disease started and the physician might only be able to mark the time when the diagnosis was recognized. In milder forms of asthma, such as intermittent or mild persistent, theses features might lead to considerable under-diagnosis, mostly due to under-presentation of respiratory symptoms by asthmatic patients to their family doctor.[94] The data in this study, therefore, might represent more doctor-diagnosed asthma than its true incidence.

One of the strong points of the system designed by the Portuguese Sentinel Network and other similar organisations in other parts of the world is a relatively stable denominator that can be used for epidemiological studies. The burden of frequent health problems in primary health care

can be studied this way. Incidence estimates and the use of medication and referrals are also common aspects studied in the PSPN.

The clinical data gathered in every encounter by the physicians participating in the PSPN has an immense potential to produce relevant health information. Using a properly designed electronic patient record linked to a well structured health information system and a family practice-based research network could be a key instrument to study chronic conditions in the community. This combination of practice-based research tools can go much beyond the simple estimation of incidence and prevalence rates or the impact of diseases in the consultation, to a more sound clinical research network. It is possible to study the natural history of diseases, reasons for consulting, test ordering, prescription patterns, referrals, and many other topics.

Portuguese family physicians have relatively stable patient lists. The age-gender distribution of the lists is updated yearly and reported to the PSPN coordination centre. The PSPN uses the physicians' lists as a denominator for estimating incidence rates. Whenever participating doctors are absent for prolonged periods from their practices, their lists are removed from the denominator for statistical purposes. Nevertheless, problems have been reported with the accuracy of the patient lists of Portuguese family physicians, including duplicate registration of patients and failure to update lists following patient transfers and deaths, so some calculations might be imprecise due to these problems.

A possible source of under-diagnosis could be that, in Portugal, younger asthmatic patients are often cared for by secondary care specialists, either in a hospital outpatient setting or in private consultations. As many of them are registered with a family physician and make frequent visits to the practice, the family doctor should have accurate information on the diagnosis, though asthma might not always be recorded in the medical records. Asthma is also often under-diagnosed in elderly patients as early symptoms of asthma often tend to be confused with symptoms of other chronic diseases such as COPD or cardiac insufficiency. [95] Family physicians are in a unique position to distinguish these conditions as they know the natural history of the disease in their patients.

The diagnostic criteria for asthma used in this study were the criteria in the 2005 GINA guidelines. [96] The questionnaire was constructed using these guidelines but was not validated. Though this could be a source of instrument bias, it is based on sound clinical features and well established diagnostic criteria.

The findings of the survey "*Asthma in an Urban Population in Portugal: A prevalence study"* represent a good estimate of the prevalence of asthma in this population. A stratified random sample was drawn from accurate patient lists and there was a good response rate. In the case of non-responders, replacements were drawn from a list of alternates also randomly produced. The non-responders were studied and there were no demographic differences found between non-responders and the study sample, but this could be a possible source of selection bias.

The population described in the general practice in the current study is believed to be representative of Matosinhos therefore these findings most likely represent the prevalence of asthma in this population.

The physician questionnaire was constructed using the guidelines in the GINA 2006 Report.[97] Questions were asked about the presence of wheezing, past or present history of dry cough, recurrent wheeze, dyspnoea/recurrent difficulty in breathing or recurrent chest tightness and the evidence of reversibility of airflow obstruction after administration of a short acting bronchodilator through clinical observation only, peak flow measurement or spirometry. The same questionnaire was used in a study on the incidence of asthma and accuracy of diagnosis in the Portuguese sentinel practice network.[98] Though its structure was simple, it is not a clinically, sociologically and culturally validated instrument. This might be a source of instrument bias.

The same can be said for the patient questionnaire as no validation procedure was conducted prior to this study and this could be another source of instrument bias. However the patient questionnaire was based on questions from the ISAAC questionnaire, and these items have been previously used in Portugal, [99] as well as in many other international studies.

The use of accepted diagnostic criteria validated by additional interview and examination by physicians in cases of doubt regarding the diagnosis also increases confidence in the quality of the data.

Evidence of reversibility of airflow obstruction after administration of a short acting bronchodilator was a requirement but it could be obtained from clinical observation, such as improvement in wheezing after bronchodilation, significant improvement in PEF measurement or through spirometry performed in the clinic or in a certified laboratory.

In some age groups the wide confidence intervals for the prevalence of asthma is due to the small numbers of cases found.

Some of the limitations of the study on enablement and quality of life in asthma patients addressed in this section have been previously dealt with in the discussion section of the study that was submitted for publication. In order to add to the general discussion of the thesis, some of these problems are clarified here.

The limitations existing in the assessment of the levels of severity of asthma based on criteria from the GINA Report update from 2008 have already been addressed in the discussion section of the paper. A complementary approach was used by matching the medication in use with the level of severity. Considering that some patients might need to step up or step down treatment thus changing their classification to a higher or lower level, might be a source of bias in the classification of severity.

Another limitation is the use of questionnaires that have not been validated. The cultural and sociological validations of the Asthma Control Test have not been published, though several Portuguese studies used the current format and its clinical use is common both in secondary and primary health care. Its use was considered reliable for this study. The modified Patient Enablement Instrument has not been validated for use in Portugal, though there were two forward and backward translations and a pilot study in a small sample to test its cultural understanding by patients.

The distribution of levels of severity of asthma observed in the sample population is different from some other studies. One Spanish survey from primary health care found a similar distribution to that in our study. [100]

The proportion of controlled asthma described in the present study was found to be higher than that reported in the general Portuguese population in a preliminary report from a national survey.[101]

The existing literature has demonstrated a good relationship between asthma control and quality of life. [102-104] This was also one of the major findings in this study.

Problems with the mPEI

There are few studies available in the scientific literature on patient enablement in asthma.

During the preparation of the EQLAP study, the researchers were faced with the challenge of finding a valid and reliable tool to measure enablement. Haughney's study from 2007 had developed the modified Patient Enablement Instrument. [45] This was the only existing validated tool

that allowed a quantitative measure of enablement. Haughney and colleagues are currently developing a new tool, the Aberdeen Asthma Questionnaire but this is not yet available. In a paper presented in the European Respiratory Society meeting in Stockholm, 2007, [105] they attempted to find out if enablement could be described and if so, if it could be measured by an appropriate tool. Focus groups and a modified Delphi exercise involving people with asthma, health care professionals and researchers had been conducted to identify a meaningful vocabulary and to generate items for inclusion in the draft questionnaire. This resulted in a 13 item draft questionnaire that was then tested amongst 102 people with asthma. The instrument was later reduced to seven items. Haughney has suggested that this new tool would solve some of the problems with the use of the mPEI, but the new instrument is not yet available. Thus the only available instrument for the measurement of patients' enablement in asthma was the mPEI.

In their study of the mPEI, Haughney et al had also found a low correlation between the mPEI and the Mini-AQLQ but found a significant correlation between the modified PEI total score and the change in Mini-Asthma Quality of Life Questionnaire score.[45] These findings suggest that the mPEI is responsive to a change in a patient's quality of life.

The results from the EQLAP study show that the mPEI has considerable limitations. The correlation between enablement (mPEI) and age was low. However when the mPEI is studied in two classes, older patients have a significantly lower level of enablement. There is a significant difference between the mean mPEI score in males and females in the study sample, with males having higher mPEI scores.

In the bivariate analysis performed to assess the association between enablement (mPEI) and other measures, no significant associations were found with quality of life (Mini-AQLQ score), asthma control (ACT score), asthma severity or the level of %FEV1 and %PEF.

Regarding the relationship between enablement (mPEI) and socio-economic status (Graffar), the results indicate that the mPEI score is worse in the lower socio-economic status groups, though there is not statistically significant. The correlation between the level of education and enablement assessed and no significant association was found. During the collection of data, some of the researchers found that patients with intermittent asthma that had been symptom-free for long periods and not using asthma relief medication, mentioned that they could only answer the mPEI questions by scoring 0 (not applicable). This was based on the instructions provided by the researchers, following the instructions given in the original paper on the mPEI.

This might explain the low mPEI scores in patients with good asthma control and intermittent asthma who were not using control or relief medication. Some of the analysis performed might have been influenced by this fact.

The analysis of data and the discussion of the findings from this study, suggest that the mPEI may be more appropriate for patients with persistent forms of asthma with measurements made before and after a consultation. This leaves some unanswered questions about the instrument and an open field for further research.

A valid and reliable instrument is required to measure patient enablement. After translation and cultural validation, the Aberdeen Asthma Questionnaire could be a useful tool for research and clinical practice.

Comparison of results with previous work

The three surveys presented in this thesis have been published or submitted in the last 24 months. Most of the comparison of the findings with other studies has been thoroughly discussed in the external validation section of those papers. In order to find more recent studies that could be compared with the studies included in this thesis, the candidate searched the literature with the appropriate MeSH terms.

1. Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network

The date of submission of this paper was 30th July 2009. A literature search was performed the 12th of June, 2011 using the combined keywords "asthma" AND "incidence" in the title and setting a time limit of 2009 to 2011. The search was done in Pubmed and Google Scholar and returned 19 and 31 articles respectively. There was overlapping of articles and Google Scholar returned several duplicates.

The abstracts were evaluated to determine whether the studies would be of value to contribute further to the discussion. Many articles studied asthma in children pregnant women and other sub-groups, therefore were not eligible.

One article was found that could be used for comparison. Gershon et al studied trends in asthma incidence in Ontario, Canada from 1996 to 2005 and concluded that the overall age- and sex-standardized incidence rate of asthma had increased from 5.0/1,000 person years to 5.7/1,000

person-years. [106] These rates are double the rate of 2.02/1,000 person years reported in the Portuguese Sentinel Practice Network survey.

A second study provided valuable methodological information about the evaluation of the validity of the case definition and a description of the participants' characteristics and health-care use patterns. It is a description of the organisation of an asthma incidence surveillance system using voluntary reporting of asthma by outpatient clinics and emergency departments. This study, however, does not contain additional data for comparison with the Portuguese Sentinel Practice Network survey. [107]

2. Asthma in an Urban Population in Portugal: A prevalence study.

The date of submission of this paper was 29 October 2010. A literature search was performed the 12th of June, 2011 using the combined keywords "asthma" AND "prevalence" in the title and setting a time limit of 2010 to 2011. The search was done in PubMed and Google Scholar and returned 136 and 100 articles respectively. There was overlapping of articles and Google Scholar returned several duplicates.

The abstracts were appraised to decide whether the studies would be of value to contribute further to the discussion. Many articles studied asthma prevalence in children, workers, ethnic minorities or other sub-groups. All the surveys that dealt with prevalence in all age groups were selected. Some studies dealing with children that had similar age intervals to the ones in the Matosinhos sample were used for comparison. Fifteen papers were selected. The main findings from each study that are relevant for comparison are discussed in the following paragraphs.

Asthma in all age groups

During 2006–2008 the CDC analysed data from the National Health Interview Survey (NHIS) and estimated that 7.8% of the U.S. population had current asthma. Current asthma prevalence also was higher among children (9.3%) than among adults (7.3%) and among females (8.6%) than among males (6.9%). [108]

According to the US National Health Statistics Reports, in 2009, current asthma prevalence was 8.2% of the U.S. population (24.6 million people); within population subgroups it was higher among females, children, persons of non-Hispanic black and Puerto Rican race or ethnicity,

persons with family income below the poverty level, and those residing in the Northeast and Midwest regions. [109]

Ekerljung et al assessed changes in the prevalence of asthma and respiratory symptoms in a defined study area in Stockholm, Sweden, using identical methods and report an increase in ever asthma from 8.7% in 1996 to 11.0% in 2007 and physician-diagnosed asthma from 7.6% to 9.3%. [110]

Another Swedish study was done in the regions of Gothenburg, Uppsala and Umeå in an age interval of 20–44 years. Subjects were surveyed both in 1990 (n = 8,982) and 2008 (n = 9,156). Current asthma rose from 6.0% to 8.0%. [111]

Fukutomi et al conducted population-based surveys three times in the same region, in 1985, 1999, and 2006, at Fujieda City, Shizuoka, Japan, and found that prevalences of lifetime asthma and current asthma had significantly increased from 1999 to 2006 (5.1% to 6.7%, and 1.5% to 3.4%, respectively). [112]

In an Italian study based on an adult representative national sample using information obtained from the Health Search Database from the Italian College of General Practitioners 6.10% of the entire population had asthma (5.49% of men and 6.64% of women). [113]

A study was done in the Canaries, Spain to evaluate the prevalence of and risk factors for asthma and related conditions. The subjects completed a respiratory questionnaire, and underwent spirometry, bronchial hyperresponsiveness (BHR) test, skin tests and immunoglobulin E (IgE) measurements. The random sample included 593 subjects. The prevalence of 4.2% (95%CI, 2.5-5.9) was found for asthma. [114]

Al the figures from the previous studies are lower than the 10.24% (95% CI: 8.16 to 12.32) found in the Matosinhos survey (Table 2).

In the Australian study by Chittleborough et al the prevalence of asthma was 12.0% (95% CI: 11.1 to 13.1), and was significantly higher among women (13.5%) than men (10.5%). Asthma was determined from spirometry and self-reported doctor diagnosis. [115]

Gershon et al studied trends in asthma prevalence in Ontario, Canada from 1996 to 2005 and concluded that the age- and sex-standardized asthma prevalence increased from 8.5% in 1996 to 13.3% in 2005, a relative increase of 55.1% ($P < 0.0001$). [106]

The prevalence referred in these two studies is higher than that found in the Matosinhos survey where no statistically significant difference in the prevalence of asthma by gender for the total population was present (Table 2).

Asthma in children and adolescents

A cross-sectional study of 3,015 adolescents (13-14 years of age) was done in Fortaleza, Ceará State, Brazil, in public and private schools, using the protocol from the International Study of Asthma and Allergies in Childhood (ISAAC), in 2006-2007. Prevalence rates were 22.6% for asthma, with a predominance of females (p = 0.002). [117]

Two thousand and twenty-three Greek 9-10-year-old schoolchildren from Athens and Thessaloniki were included in the study. All participants followed the ISAAC-II protocol by questionnaire, skin prick testing and flexural dermatitis examination. Compared with Athens, the prevalence of lifetime asthma (11.5% vs. 7.7%, p=0.004) and atopic current asthma (3.2% vs. 1.6%, p=0.02), were higher in Thessaloniki. [117]

Bjerg et al compared two population-based cohorts of 7 to 8-year olds from the same Swedish towns in 1996 and 2006 using parental expanded ISAAC questionnaires. There was an increase on the diagnoses of asthma from 5.7% to 7.4% (p = 0.010). [118]

Bai et al studied the prevalence of asthma in children aged 0 to 14 years from Beijing, Chongqing, and Guangzhou and found 3.15%, 7.45%, and 2.09%, respectively. [119]

A cross-sectional epidemiological study following ISAAC methodology, and using a written questionnaire was distributed in schools in the Autonomous Community of Galicia. The study sample included 6-7 year-old children and 13-14 year-old adolescents, all of them from Galician Health Areas. The estimated prevalence of asthma was 13.6% in younger children and 12.2% in adolescents. [120]

A Portuguese survey was done in Lisbon in 2008. Parents of 900 students aged 5-12 years were invited to answer a questionnaire of the ISAAC. The prevalence of asthma was 5.6%. [121]

In the Matosinhos survey, the prevalence of asthma in the 0 to 7 years was 9.56% (95% CI: 5.41 to 13.71 and in the 8 to 19 years 13.13% (95% CI: 8.74 to 17.52). Table 3 shows the comparison of the Matosinhos survey with the other studies.

Table 2: International comparison of asthma prevalence rates for all age groups in surveys published in 2010-11. Update of the Table 5 from the paper "*Asthma in an Urban Population in Portugal*". [122]

Year	Study	Country	Prevalence %
2011*	Juliá-Serdá et al. [114]	Spain	4.2
2008	Bjerg et al. [111]	Sweden	8.0
2009	US National Health Statistics Reports. [109]	USA	8.2
2007	Ekerljung et al. [110]	Sweden	11.0
2009*	Chittleborough et al. [115]	Australia	12.0
2009	**Correia-de-Sousa et al.** [122]	Portugal	**10.2**
2006	Fukutomi et al. [112]	Japan	6.7
2006-2008	National Health Interview Survey. [108]	USA	7.8
2009	Cazzola et al. [113]	Italy	6.10
2005	Gershon et al. [106]	Canada	13.3

* Year the paper was submitted. The year of the survey could not be confirmed in the paper

Table 3: International comparison of asthma prevalence rates for children and adolescents in surveys published in 2010-11.

Year	Age group	Study	Country	Prevalence %
2008-2009	0 to 14	Bai et al. [119]	China (Guangzhou)	2.09
2008-2009	0 to 14	Bai et al. [119]	China (Beijing)	3.15
2008-2009	0 to 14	Bai et al. [119]	China (Chongqing)	7.45
2009	0 to 7	**Correia-de-Sousa et al**. [122]	Portugal (Matosinhos)	**9.56**
2008	5 to 12	Pegas e tal. [121]	Portugal (Lisbon)	5.6
2006-2007	6 to 7	López-Silvarrey-Varela et al. [120]	Spain (Galicia)	13.6
2006	7 to 8	Bjerg et al. [118]	Sweden	7.4
2009	8 to 19	**Correia-de-Sousa et al**. [122]	Portugal (Matosinhos)	**13.13**
2000 - 2001	9 to 10	Papadopoulou et al. [117]	Greece	11.5
2006-2007	13 to 14	López-Silvarrey-Varela et al. [120]	Spain (Galicia)	12.2
2006 – 2007	13 to 14	de Luna et al. [116]	Brasil	22.6

3. Enablement and quality of life in asthma patients (the EQLAP study): a cross-sectional study from a family practice

No further studies were found to add to this section, as the relevant ones have been included in the discussion section of the survey.

Clinical and scientific implications of the findings

1. Asthma incidence and accuracy of diagnosis in the Portuguese sentinel practice network

According to the data from this study, the diagnoses of asthma made by the family physicians in the research network were accurate in 84% of all reported cases, as confirmed by reference to the diagnostic criteria used. These findings suggest that well trained family physicians have the skill to identify patients with asthma and perform the recommended diagnostic procedures.

The incidence rate reported of 2.02 cases/1000/ year means that an average family physician with a list of 1800 patients, should expect to see three to four new patients with asthma every year.

Based on data from the survey, for a population of 10,893,010 a figure of 22,004 new cases of asthma per year should be expected in Portugal.

The implications of these figures at the secondary health care level are related to the increase in the required investigations to confirm diagnosis through spirometry, to perform tests to study allergies and to deal with some of the more severe forms of disease.

Health authorities need to assess the increase in health costs at all levels, the human resources needed, the additional training required, the costs of diagnostic investigations, the increase in the use of treatment and, for a minority of uncontrolled patients, the use of emergency services and hospital admissions.

2. Asthma in an Urban Population in Portugal: A prevalence study.

The use of the best available information about asthma both from patients and the family physician has demonstrated to be a good approach to estimate with higher precision the prevalence of asthma in a community.

The 10% prevalence of asthma found in the present study was within the expected interval. This is an important epidemiological result and can support local health authorities in the allocation of human and financial resources to deal with the problems.

From the clinical management point of view, information about expected community prevalence can assist clinicians and practices in comparing results and increasing their awareness on the need for a better diagnosis of asthma. The discussion of the results from the survey at local level and the dissemination through publishing and the presentation at scientific meetings, have contributed to a wider perception of the burden of asthma in the community.

Further studies in other regions of Portugal using the same diagnostic criteria and sampling methods should be done in order to confirm these findings.

Based on data from this survey, assuming a prevalence of asthma of 10%, with the current population of Portugal of 10,893,010 in 2011, we may expect 1,089,301 persons to have asthma in Portugal. These figures might help National health authorities to develop plans to deal

with asthma and, due to its dimension, include asthma control as one of the main health problems requiring attention.

3. Enablement and quality of life in asthma patients (the EQLAP study): a cross-sectional study from a family practice

Asthma control was found to be associated with quality of life in a population of asthmatics treated in family practice. These findings reinforce the need for improvement in the care of patients with asthma in primary health care.

The patients with asthma in the survey showed good degree of asthma control, as asthma was partially or totally controlled in 70.9%. Their family physicians have the capability to achieve a good level of care of asthma among their patients. These findings suggest that the care of most patients with less severe forms of asthma should be in the hands of well trained family physicians.

A considerable number of patients with intermittent asthma did not report symptoms or the use of medication. In order to be sure that this is not due to a low level of self-awareness of symptoms, clinical record reviews should be performed at regular intervals, inviting these patients for appointments. The routine use of adequate clinical tools such as ACT, CARAT or Mini-AQLQ can support clinicians to achieve a more structured approach to the control of asthma in cooperation with other health professionals and enabled patients.

The cut-off level established for the mini AQLQ can help researchers and clinicians to use this tool and include the assessment of quality of life in asthmatic patients as a routine, when caring for patients with more severe forms of the disease.

The problems encountered with the use of the mPEI in assessing patient enablement did not allow any sound conclusions about the level of enablement of asthmatic patients in the survey. The observed lower level of enablement in some sub-groups, such as females, older, less educated and less wealthy patients, though not statistically significant, is clinically meaningful and supports research from other sources that physicians and patients may benefit from efforts to improve patient enablement in order to improve the care of chronic diseases such as asthma.

Conclusions

Conclusions

The findings from the studies conducted suggest that Portuguese family physicians are skilled in diagnosing asthma with an accuracy of 84%.

The annual incidence of asthma in the general population in Portugal was 2.02 cases/1000/ year.

The use of the best knowledge about asthma from both the patient and the physician is a good strategy for the determination of the prevalence of asthma in a community survey.

The prevalence of asthma in the urban community studied was 10.24%.

Family Physicians from Matosinhos have the capability to achieve a good level of asthma control among their patients. Asthma was partially or totally controlled in 70.9%.

Asthma control and quality of life are strongly correlated.

A cut-off value for the score of the quality of life measurement using the mini-AQLQ was established at 5.4.

The results show a mean score of the mPEI of 6.5, thus indicating a clinically meaningful enablement.

Suggestions for future research

Suggestions for future research

Since 1999, asthma and respiratory diseases have emerged as a natural field of research and academic development for me, while preserving interest and activity in other clinical, scientific and academic fields. I have since attended many scientific meetings and participated in organisations such as the Portuguese GINA Group, IPCRG, or the newly formed GRESP (the Portuguese respiratory interest group of family physicians).

In my academic activity I was able to be a tutor of research projects of students from the University of Minho Medical School in the respiratory area. As a trainer of vocational trainees in family medicine, I also involved some of the trainees and young family physicians in research in respiratory problems in family practice.

While developing the research presented in this thesis it was possible to incorporate new projects and research ideas and to develop some of them to guarantee continuity.

Two projects have already emerged while this thesis was being written.

1. Improving Care of Asthma Patients in Portugal through improvements in the electronic medical record: A proposal for a pilot study of new technology in Portuguese primary medical care.

   ICAPP-EMR "Improving Care of Asthma Patients in Portugal - Electronic Medical Record" is an asthma audit and review pilot study developed by the Department of Community Health of the School of Health Sciences of the University of Minho in conjunction with the International Primary Care Research Group (IPCRG) using electronic patient data to facilitate the flow of information between the patient and physician and to allow the monitoring of quality indicators in clinical practice. The objective of this study is to develop an effective tool for recording of asthma care in the electronic medical record and to determine if it is feasible in the National Health Service.

   Research questions: Does improved recording of asthma care using items from the IPCRG guidelines improve the outcomes of asthma control for asthma patients? Are patient compliance, concordance and enablement associated with better asthma control and outcomes?

Methods: A recording scheme for asthma care based on nationally accepted guidelines will be developed through a consensus method (adapted Delphi). This will include items in the patient's history, physical examination, ancillary diagnostic tests, recording of the diagnosis, choice of treatment, patient concordance and follow-up. The researchers will assist computer programmers in the development of pilot software to be added to the electronic medical record currently in use Portuguese National Health Service. Special attention will be given to indicators of patient compliance, concordance and enablement.

A sample of practices and doctors will be selected for participation in the study. A sample of asthma patients will be selected from each practice and the patient records will be reviewed to determine the number of items from the ideal record that are currently in the patient's record. A random sample of participating practices will receive the new electronic asthma flow sheet and instructions on its use. A control group will continue with usual care.

At the end of the study period, the charts of a sample of asthma patients will be reviewed to look for changes in recording patterns. Evidence for differences in asthma control will also be assessed.

Importance: If this instrument appears to be feasible and effective, it may contribute to the ease of asthma care by general practitioners and improve the quality of life for asthma patients.

This may lead to a recommendation to the National Health Service Administration for the adoption of asthma control quality indicators and the addition of the asthma control tool in the Portuguese NHS electronic medical record.

2. The second study was named Improving Care of Asthma Patients in Portugal through the development of Adherence, Concordance, and Enablement (ICAPP ACE).

   The researchers' team will initially develop and validate translations and cultural adaptations of assessment tools such as the Modified Morisky Scale and the Aberdeen Asthma Questionnaire. The Control of Allergic Rhinitis and Asthma Test (CARAT) will be used to assess asthma control.

In a second phase, the team will develop a survey to study the relationship between patient compliance, concordance and enablement with better asthma control and outcomes.

Importance: If these instruments appear to be useful, it may contribute to its use in practice thus assisting family physicians in understanding better their patients and improve the quality of life for asthma patients.

This may lead to a recommendation to the National Health Service for the adoption of asthma quality of life instruments and the addition of the CARAT tool in the Portuguese NHS electronic medical record.

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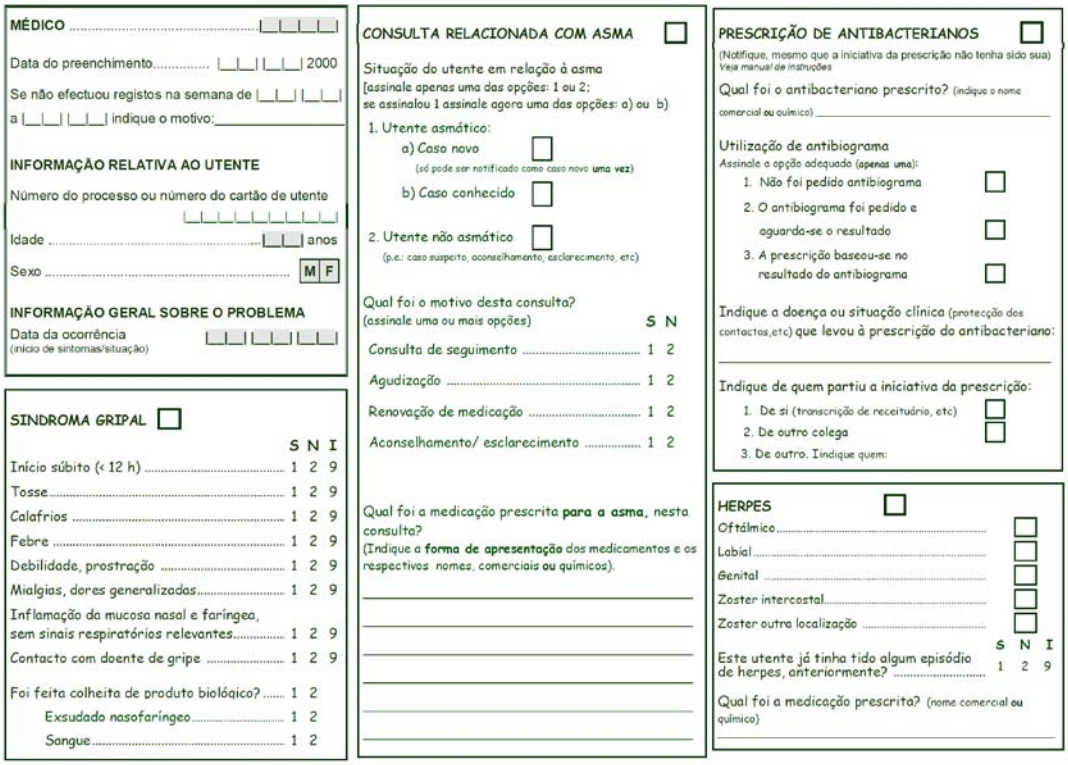
Appendixes

Appendix 1 - Portuguese Sentinel Practice Network record form



MÉDICO ..... |_|_|_|_|

Data do preenchimento..... |_|_| |_|_| 2000

Se não efectuou registos na semana de |_|_| |_|_|

a |_|_| |_|_| indique o motivo:_____

INFORMAÇÃO RELATIVA AO UTENTE

Número do processo ou número do cartão de utente

|_|_|_|_|_|_|_|_|_|_|

Idade ..... |_|_| anos

Sexo ..... M F

INFORMAÇÃO GERAL SOBRE O PROBLEMA

Data da ocorrência (início de sintomas/situação) |_|_| |_|_| |_|_|

SINDROMA GRIPAL ☐

	S	N	I
Início súbito (< 12 h)	1	2	9
Tosse	1	2	9
Calafrios	1	2	9
Febre	1	2	9
Debilidade, prostração	1	2	9
Mialgias, dores generalizadas	1	2	9
Inflamação da mucosa nasal e faríngea, sem sinais respiratórios relevantes	1	2	9
Contacto com doente de gripe	1	2	9
Foi feita colheita de produto biológico?	1	2	
Exsudado nasofaríngeo	1	2	
Sangue	1	2	

CONSULTA RELACIONADA COM ASMA ☐

Situação do utente em relação à asma
[assinale apenas uma das opções: 1 ou 2;
se assinalou 1 assinale agora uma das opções: a) ou b)

1. Utente asmático:
   a) Caso novo ☐ (só pode ser notificado como caso novo **uma vez**)
   b) Caso conhecido ☐
2. Utente não asmático ☐ (p.e.: caso suspeito, aconselhamento, esclarecimento, etc)

Qual foi o motivo desta consulta? (assinale uma ou mais opções)

	S	N
Consulta de seguimento	1	2
Agudização	1	2
Renovação de medicação	1	2
Aconselhamento/ esclarecimento	1	2

Qual foi a medicação prescrita **para a asma**, nesta consulta?
(Indique a **forma de apresentação** dos medicamentos e os respectivos nomes, comerciais **ou** químicos).

_____
_____
_____
_____
_____
_____

PRESCRIÇÃO DE ANTIBACTERIANOS ☐

(Notifique, mesmo que a iniciativa da prescrição não tenha sido sua)
Veja manual de instruções

Qual foi o antibacteriano prescrito? (indique o nome comercial **ou** químico) _____

Utilização de antibiograma
Assinale a opção adequada (**apenas uma**):

1. Não foi pedido antibiograma ☐
2. O antibiograma foi pedido e aguarda-se o resultado ☐
3. A prescrição baseou-se no resultado do antibiograma ☐

Indique a doença ou situação clínica (protecção dos contactos,etc) que levou à prescrição do antibacteriano:

_____

Indique de quem partiu a iniciativa da prescrição:

1. De si (transcrição de receituário, etc) ☐
2. De outro colega ☐
3. De outro. Indique quem:

HERPES ☐

Oftálmico	☐
Labial	☐
Genital	☐
Zoster intercostal	☐
Zoster outra localização	☐

	S	N	I
Este utente já tinha tido algum episódio de herpes, anteriormente?	1	2	9

Qual foi a medicação prescrita? (nome comercial **ou** químico)

_____

Appendix 2 - Questionnaire used for the study on Accuracy of diagnosis of new cases of asthma

Estudo dos Novos casos de Asma na Rede Médicos Sentinela 2000-2003

MÉDICO |_|_|_|_| **Data de ocorrência** (dia / mês/ano) __/__/__

Caracterização do Utente

Idade |_|_| anos **Sexo** |**M**|**F**| **Nº processo ou cartão de utente** _____

Critérios de Diagnóstico

		S	N	I
1.	Pieira / Sibilos (sons sibilantes à expiração, especialmente em crianças)	1	2	9
2.	História de um dos seguintes sintomas:			
2.1	Tosse seca com agravamento nocturno	1	2	9
2.2	Pieira ou sibilância recorrente	1	2	9
2.3	Dispneia / dificuldade respiratória recorrente	1	2	9
2.4	Opressão ou aperto torácico recorrente	1	2	9
3.	Evidência de reversibilidade do broncoespasmo com broncodilatador de acção rápida confirmada por:			
3.1	Observação Clínica	1	2	9
3.2	DEMI / PEF	1	2	9
3.3	Espirometria	1	2	9

Circunstâncias do Diagnóstico

4. Quem fez o diagnóstico:

- Médico de Família ☐
- Pediatra ☐
- Pneumologista ☐
- Alergologista ☐
- Outro ☐

5. Onde foi feito o diagnóstico:

- Centro de Saúde / consulta do seu MF ☐
- Centro de Saúde / consulta de substituição, SAP ou outra ☐
- Ambulatório de outra especialidade ☐
- Consulta externa de hospital ☐
- SU de hospital ☐
- Médico Privado ☐

Outros exames complementares de diagnóstico efectuados

		S	N	I
6.	Testes cutâneos (Prick)	1	2	9
7.	Espirometria	1	2	9
8.	Radiografia pulmonar	1	2	9
9.	Análises *(Pedidas no âmbito do diagnóstico da asma)* *	1	2	9
10.	Outros Quais? _____	1	2	9

*Exemplo: hemograma, IgE Total, IgE específicas (Phadiotop ou RAST), exame parasitológico de fezes

Muito obrigado pela sua colaboração !

Appendix 3 - Physician's questionnaire from the study "Asthma in an Urban Population in Portugal: A prevalence study"

Questionário do Médico

Estudo da prevalência de asma no Centro de Saúde de Matosinhos

MÉDICO |_|_|_|_| (nº mecanográfico) **Data de preenchimento** (dia/mês/ano) __/__/__

Caracterização do Utente

Idade |_|_| anos **Sexo** |M|F| **NOP** _____

ESTE UTENTE TEM ASMA?	S	N	I

Se este utente tem asma, explicite quais os critérios em que se baseou o diagnóstico

		S	N	I
1.	Pieira / Sibilos (sons sibilantes à expiração, especialmente em crianças)	1	2	9
2.	História de um dos seguintes sintomas:			
2.1	Tosse seca com agravamento nocturno	1	2	9
2.2	Pieira ou sibilância recorrente	1	2	9
2.3	Dispneia / dificuldade respiratória recorrente	1	2	9
2.4	Opressão ou aperto torácico recorrente	1	2	9
3.	Evidência de reversibilidade do broncoespasmo com broncodilatador de acção rápida confirmada por:			
3.1	Observação Clínica	1	2	9
3.2	PEF	1	2	9
3.3	Espirometria	1	2	9

		S	N	I
4.	Se o diagnóstico não foi feito por si, tem informação clínica ou de função respiratória que o valide?			

Muito obrigado pela sua colaboração!

Appendix 4 - Patient's questionnaire from the study "Asthma in an Urban Population in Portugal: A prevalence study"

Estudo da prevalência de asma no Centro de Saúde de Matosinhos

MÉDICO |_|_|_|_| (nº mecanográfico) **Data de preenchimento** (dia/mês/ano) __/__/__

Caracterização do Utente

Idade |_|_| anos **Sexo** |M|F| **NOP** _____
Data de nascimento (dia / mês/ano) __/__/__

Sintomas

1. Já alguma vez teve pieira ou chiadeira (gatinhos) no peito? Sim Não Ignoro
Se respondeu não, por favor passe à questão nº 6

2. Teve pieira ou chiadeira (gatinhos) no peito nos últimos 12 meses? Sim Não Ignoro
Se respondeu não, por favor passe à questão nº 6

3. Quantos ataques de pieira ou chiadeira (gatinhos) teve nos últimos 12 meses?
Nenhum |_| 1 a 3 |_| 4 a 12 |_| Mais de 12 |_|

4. Nos últimos 12 meses teve pieira ou chiadeira (gatinhos) no peito durante ou depois de fazer exercício? Sim Não Ignoro

5. Nos últimos 12 meses alguma vez acordou devido à pieira ou chiadeira (gatinhos)? Sim Não Ignoro

6. Nos últimos 12 meses teve tosse seca à noite para além da tosse associada a uma constipação ou infecção respiratória? Sim Não Ignoro

7. Já alguma vez teve asma? Sim Não Ignoro

8. Alguma vez algum médico lhe disse que tinha asma? Sim Não Ignoro

Medicação

9. Nos últimos 12 meses usou algum inalador (bomba) azul (Bricanyl ou Ventilan) para a falta de ar ou asma? Sim Não Ignoro

10. Nos últimos 12 meses usou algum inalador verde (Oxis, Formoterol, Serevent, Dilamax ou Ultra-Beta) para a falta de ar ou asma? Sim Não Ignoro

11. Nos últimos 12 meses usou algum inalador castanho/ laranja (Pulmicort, Flixotaide, Brisovent, Asmo-Lavi ou Budesonido) para a falta de ar ou asma? Sim Não Ignoro

12. Nos últimos 12 meses usou algum inalador lilás / roxo/ vermelho (Symbicort, Assieme, Seretaide, Brisomax, Veraspir ou Maizar) para a falta de ar ou asma? Sim Não Ignoro

13. Nos últimos 12 meses usou alguma vez comprimidos (Singulair, Lukair ou Accolate) para a falta de ar ou asma? Sim Não Ignoro

Muito obrigado pela sua colaboração !

Appendix 5 – English version of the Physician's questionnaire from the study "Asthma in an Urban Population in Portugal: A prevalence study"

APPENDIX 2: PHYSICIAN QUESTIONNAIRE

Asthma prevalence study in Matosinhos Health Centre

Physician |_|_|_|_| (code) **Date** (day/month/year) __/__/_____

Patient's data

Age |_|_| years **Gender** |M|F| **Code** _____

DOES THIS PATIENT HAVE ASTHMA?			Y	N	I
If this patient has asthma mark down the criteria that supported the diagnosis					
			Y	N	I
1.	Wheezing		1	2	9
2.	Past or present history of one of the following symptoms:				
	2.1	Dry cough (worse particularly at night)	1	2	9
	2.2	Recurrent wheeze	1	2	9
	2.3	Dyspnoea / Recurrent difficulty in breathing	1	2	9
	2.4	Recurrent chest tightness	1	2	9
3.	Evidence of reversibility of airflow obstruction after a short acting bronchodilator through:				
	3.1	Clinical observation (mainly in children)	1	2	9
	3.2	PEF	1	2	9
	3.3	Spirometry	1	2	9
4.	If the diagnosis was not made by you, do you have data from a hospital specialist that validates it?		1	2	9

Thank you for your assistance!

Appendix 6: Patient's questionnaire from the study "Asthma in an Urban Population in Portugal: A prevalence study"

APPENDIX 3: PATIENT QUESTIONNAIRE

Asthma prevalence study in Matosinhos Health Centre

Physician |_|_|_|_| (code) **Date** (day/month/year) __/__/_____

Patient's data

Age |_|_| years **Gender** |**M**|**F**| **Code** _____

Symptoms

1.	Have you ever had wheezing?	Yes	No	I ignore
	If you answered no, please move to question number 6			
2.	Have you had wheezing in the last 12 months?	Yes	No	I ignore
	If you answered no, please move to question number 6			
3.	How many attacks of wheezing have you had in the last 12 months? None |_| 1 to 3 |_| 4 to 12 |_| More than 12 |_|			
4.	In the last 12 months have you had wheezing during or after exercising?	Yes	No	I ignore
5.	In the last 12 months did you ever wake up because of your wheezing?	Yes	No	I ignore
6.	In the last 12 months have you had dry cough at night, except for cough associated with an upper respiratory tract infection (common cold)?	Yes	No	I ignore
7.	Have you ever had asthma?	Yes	No	I ignore
8.	Have you ever been told by a doctor that you had asthma?	Yes	No	I ignore

Medication

9.	In the last 12 months did you ever use a blue inhaler (Bricanyl or Ventilan) for your shortness of breath or asthma?	Yes	No	I ignore
10.	In the last 12 months did you ever use a green inhaler (Oxis, Formoterol, Serevent, Dilamax ou Ultra-Beta) for your shortness of breath or asthma?	Yes	No	I ignore
11.	In the last 12 months did you ever use a brown / orange inhaler (Pulmicort, Flixotaide, Brisovent, Asmo-Lavi ou Budesonide) for your shortness of breath or asthma?	Yes	No	I ignore
12.	In the last 12 months did you ever use a violet / purple / red inhaler (Symbicort, Assieme, Seretaide, Brisomax, Veraspir ou Maizar) for your shortness of breath or asthma?	Yes	No	I ignore
13.	In the last 12 months did you ever use tablets (Singulair, Lukair ou Accolate) for your shortness of breath or asthma?	Yes	No	I ignore

Thank you for your assistance!

Appendix 7 - Informed consent form from the study "Asthma in an Urban Population in Portugal: A prevalence study"

DECLARAÇÃO DE CONSENTIMENTO INFORMADO

O projecto **"Estudo da prevalência de asma por grupos etários e sexo na população da área coberta pelo Centro de Saúde de Matosinhos"** é realizado no âmbito de um trabalho de investigação da Escola de Ciências da Saúde da Universidade do Minho, com o propósito de estimar a prevalência da asma, por grupos etários e sexo, na população da área coberta pelo Centro de Saúde de Matosinhos.

Eu,_____,
utente inscrito na Unidade de Saúde Familiar Horizonte, portador do número operacional _____ declaro que li e compreendi este formulário de consentimento e aceito voluntariamente participar neste estudo. Declaro aceitar que as respostas às questões constantes no questionário sejam utilizadas para fins de investigação para o projecto acima referido, desde que não usadas para outro propósito que não o mencionado.

Assinatura do participante/ representante legal

Matosinhos, de de 2008

_____

Assinatura do Investigador

_____

Matosinhos, de de 2008

Appendix 8 - Questionnaire from the EQLAP Study

1. Investigador nº	1. ☐☐
2. Doente nº	2. ☐☐☐

VARIÁVEIS SOCIO - DEMOGRÁFICAS

3. Género	
0 ☐ Feminino	
1 ☐ Masculino	3. ☐
4. Idade actual (data de nascimento DDMMAAAA)	
☐☐☐☐☐☐☐☐	4. ☐☐☐☐☐☐☐☐
5. Classificação Social de Graffar	
5.1 Profissão ☐	5.1 ☐
5.2 Instrução ☐	5.2 ☐
5.3 Fonte de Rendimento ☐	5.3 ☐
5.4 Tipo de Habitação ☐	5.4 ☐
5.5 Local de Residência ☐	5.5 ☐

VARIÁVEIS ASMA

6. Grau de Gravidade de Asma	
GINA	
1 ☐ Asma Intermitente	
2 ☐ Asma Persistente Ligeira	
3 ☐ Asma Persistente Moderada	
4 ☐ Asma Persistente Grave	6. ☐
7. Fármacos	
7.1 Alívio	
0 ☐ Sem medicação	
1 ☐ Agonistas-β2 de acção rápida	
2 ☐ Anti-colinérgicos	
3 ☐ Outras terapêuticas	7.1 ☐
7.2 Controlo	
0 ☐ Sem medicação	
1 ☐ Corticóides inalados	
2 ☐ Agonistas-β2 de acção longa inalados	
3 ☐ Associação de um corticoide com um agonistas-β2 de acção longa	
4 ☐ Associação de um corticoide com um anti-leucotrieno	
5 ☐ Teofilina oral	
6 ☐ Anti-leucotrienos	
7 ☐ Outras terapêuticas	7.2 ☐
_____	
_____	

8. Comorbilidades

8.1 Concomitante

.....

.....

8.1 ⌊__⌋

8.2 Coexistente

.....

.....

8.2 ⌊__⌋

9. Controlo da Asma

mini ACT

1 ⌊__⌋ 9.1 ⌊__⌋

2 ⌊__⌋ 9.2 ⌊__⌋

3 ⌊__⌋ 9.3 ⌊__⌋

4 ⌊__⌋ 9.4 ⌊__⌋

5 ⌊__⌋ 9.5 ⌊__⌋

10. Grau de Capacitação

PEI

1 ⌊__⌋ 10.1 ⌊__⌋

2 ⌊__⌋ 10.2 ⌊__⌋

3 ⌊__⌋ 10.3 ⌊__⌋

4 ⌊__⌋ 10.4 ⌊__⌋

5 ⌊__⌋ 10.5 ⌊__⌋

6 ⌊__⌋ 10.6 ⌊__⌋

11. Qualidade de Vida

mini AQLQ

1 ⌊__⌋ 11.1 ⌊__⌋

2 ⌊__⌋ 11.2 ⌊__⌋

3 ⌊__⌋ 11.3 ⌊__⌋

4 ⌊__⌋ 11.4 ⌊__⌋

5 ⌊__⌋ 11.5 ⌊__⌋

6 ⌊__⌋ 11.6 ⌊__⌋

7 ⌊__⌋ 11.7 ⌊__⌋

8 ⌊__⌋ 11.8 ⌊__⌋

9 ⌊__⌋ 11.9 ⌊__⌋

10 ⌊__⌋ 11.10 ⌊__⌋

11 ⌊__⌋ 11.11 ⌊__⌋

12 ⌊__⌋ 11.12 ⌊__⌋

13 ⌊__⌋ 11.13 ⌊__⌋

14 ⌊__⌋ 11.14 ⌊__⌋

15 ⌊__⌋ 11.15 ⌊__⌋

12. PEF ⌊__⌋⌊__⌋⌊__⌋ 12. ⌊__⌋⌊__⌋⌊__⌋

13. FEV_1 ⌊__⌋⌊__⌋⌊__⌋ 13. ⌊__⌋⌊__⌋⌊__⌋

14. Altura (cm) ⌊__⌋⌊__⌋⌊__⌋ 14. ⌊__⌋⌊__⌋⌊__⌋

Appendix 9 - Informed consent form from the EQLAP study

Declaração de consentimento Informado

DECLARAÇÃO DE CONSENTIMENTO INFORMADO

O projecto **"Auto-controlo e Qualidade de Vida dos Doentes Asmáticos"** é realizado no âmbito de um trabalho de investigação da Escola de Ciências da Saúde da Universidade do Minho, com o propósito de avaliar a gravidade da asma, o tipo de medicação utilizada, a frequência de crises e a qualidade de vida, numa população de doentes com asma do Centro de Saúde de Matosinhos.

Eu, _____,
utente inscrito na Unidade de Saúde Familiar Horizonte, portador do número operacional _____, declaro que li e compreendi este formulário de consentimento e aceito voluntariamente participar neste estudo. Declaro aceitar que as respostas às questões constantes no questionário sejam utilizadas para fins de investigação para o projecto acima referido, desde que não usadas para outro propósito que não o mencionado.

Asseguro que fui informado de que:

1. Para a minha participação serão recolhidos dados sobre mim (sexo, idade, nível sócio-económico, controlo actual da asma e terapêutica utilizada para o controlo da asma).
2. Os dados recolhidos serão utilizados de forma completamente anónima e sem fazerem referência à minha identificação pessoal.
3. Na eventualidade da apresentação e da publicação dos resultados deste estudo, será garantida a confidencialidade da minha identidade.
4. Para a conclusão do estudo os investigadores terão acesso directo aos meus ficheiros médicos para verificação dos dados em estudo.

Assim, declaro a minha vontade em participar voluntariamente neste estudo.

Assinatura do participante
Matosinhos, _____ de _____ de 20____

_____

O doente foi por mim informado sobre a natureza e objectivo deste estudo.

Assinatura do investigador
Matosinhos, _____ de _____ de 20____

_____

Appendix 10 Mini ACT

mini ACT

Questionário para crianças acima de 12 anos e adultos:

1. Durante as últimas **4 semanas**, quanto tempo é que a **asma** o/a impediu de fazer as suas tarefas habituais no trabalho, na escola/universidade ou em casa?				
1 Sempre	2 A maior parte do tempo	3 Algum tempo	4 Pouco Tempo	5 Nunca
2. Durante as últimas **4 semanas**, quantas vezes teve falta de ar?				
1 Mais de uma vez por dia	2 Uma vez por dia	3 3 a 6 vezes por semana	4 Uma ou duas vezes por semana	5 Nunca
3. Durante as últimas **4 semanas**, quantas vezes os sintomas da **asma** (pieira, tosse, falta de ar, aperto ou dor no peito) o/a fizeram acordar de noite ou mais cedo do que é costume de manhã?				
1 4 ou mais noites por semana	2 2 ou 3 noites por semana	3 Uma vez por semana	4 Uma ou duas vezes	5 Nunca
4. Durante as últimas **4 semanas**, quantas vezes usou os seus medicamentos para alívio rápido, em inalador ou nebulizador, como por exemplo, *salbutamol*?				
1 3 ou mais vezes por dia	2 1 ou 2 vezes por dias	3 2 ou 3 vezes por semana	4 Uma vez por semana ou menos	5 Nunca
5.Como avaliaria o seu controlo da **asma** nas últimas **4 semanas**?				
1 Não controlada	2 Mal controlada	3 Mais ao menos controlada	4 Bem controlada	5 Completamente controlada

Appendix 11 Graffar Social Classification

Classificação Social de Graffar (SAM)

PROFISSÃO

1. Grandes industriais e comerciantes. Gestores de topo de grandes empresas / Administração Pública. Profissões liberais
2. Médios industriais, comerciantes e agricultores. Dirigentes intermédios e quadros técnicos das empresas / Administração Pública
3. Pequenos industriais e comerciantes. Encarregados e operários qualificados
4. Pequenos agricultores. Operários semi-qualificados, escriturários
5. Mão de obra indiferenciada

INSTRUÇÃO

1. Doutoramento. Mestrado. Licenciatura.
2. Bacharelato. Curso Superior.
3. Ensino secundário.
4. Escolaridade obrigatória segundo a idade
5. Não escolaridade obrigatória segundo a idade

FONTE PRINCIPAL DE RENDIMENTO

1. Propriedade
2. Altos vencimentos e honorários
3. Vencimentos certos
4. Remunerações incertas
5. Assistência

TIPO DE HABITAÇÃO

1. Luxuosa
2. Espaçosa e confortável
3. Bem conservada e com cozinha e WC. Electrodomésticos essenciais
4. Com cozinha e WC mas degradada e /ou sem Electrodomésticos essenciais
5. Imprópria

LOCAL DE RESIDÊNCIA

1. Bairro elegante
2. Bom local
3. Zona antiga
4. Bairro operário / social
5. Bairros de lata

Appendix 12 - Modified Patient Enablement Instrument (Portuguese Version)

PEI modificado (versão alternativa 2)

Como resultado do tratamento que tem estado a fazer para a asma, sente que é...

	Na mesma ou pior 0	Melhor 1	Muito melhor 2
1. Capaz de lidar com a vida?			
2. Capaz de compreender a sua doença?			
3. Capaz de lidar com a sua doença?			
4. Capaz de se manter saudável?			
5. Confiante na sua saúde?			
6. Capaz de resolver problemas por si?			

Em consonância com o sistema de classificação adoptado no questionário original, as respostas dos doentes foram classificadas com 0 ("Na mesma ou pior"), 1 ("Melhor") ou 2 ("Muito melhor").

Caso alguma questão não se aplique deve ser classificado como 0 ("Na mesma ou pior").

Appendix 13 - AQLQ – Asthma Quality of Life Questionnaire (Portuguese Version)

QUESTIONÁRIO DE QUALIDADE DE VIDA NA ASMA-VERSÃO REDUZIDA (PORTUGUESE VERSION) PREENCHIDO PELO DOENTE

Por favor responda a todas as perguntas pondo um círculo à volta do número que melhor descreve como se tem sentido durante as duas úitimas semanas, por ter asma.

EM GERAL, QUANTO TEMPO, DURANTE AS 2 ÚLTIMAS SEMANAS:

	Sempre	Quase sempre	Bastante tempo	Algum tempo	Pouco tempo	Quase nunca	Nunca
1. Sentiu FALTA DE AR por causa da asma?	1	2	3	4	5	6	7
2. Se sentiu incomodado/a por, ou teve de evitar um ambiente com PÓ?	1	2	3	4	5	6	7
3. Teve um sentimento de FRUSTRAÇÃO, TRISTEZA OU REVOLTA por causa da asma?	1	2	3	4	5	6	7
4. Se sentiu incomodado/a por ter TOSSE?	1	2	3	4	5	6	7
5. Teve MEDO OU RECEIO DE NÃO TER À MÃO A MEDICAÇÃO PARA A ASMA?	1	2	3	4	5	6	7
6. Teve uma sensação de APERTO NO PEITO ou de PESO NO PEITO?	1	2	3	4	5	6	7
7. Se sentiu incomodado/a por, ou teve de evitar um ambiente com FUMO DE TABACO?	1	2	3	4	5	6	7
8. Teve DIFICULDADE EM DORMIR BEM DE NOITE por ter asma?	1	2	3	4	5	6	7
9. Se sentiu PREOCUPADO/A POR TER ASMA?	1	2	3	4	5	6	7
10. Sentiu PIEIRA ("GATINHOS") no peito?	1	2	3	4	5	6	7
11. Se sentiu incomodado/a por, ou teve de evitar sair por causa do TEMPO, DO CLIMA OU DA POLUIÇÃO DO AR?	1	2	3	4	5	6	7

QUESTIONÁRIO DE QUALIDADE DE VIDA NA ASMA-VERSÃO REDUZIDA (PORTUGUESE VERSION) PREENCHIDO PELO DOENTE

ATÉ QUE PONTO É QUE SE SENTIU LIMITADO/A DURANTE AS *2* ÚLTIMAS SEMANAS AO DESEMPENHAR ESTAS ACTIVIDADES, POR TER ASMA?

	Completamente limitado/a	Extremamente limitado/a	Muito limitado/a	Moderadamente limitado/a	Pouco limitado/a	Muito pouco limitado/a	Nada limitado/a
12. ACTIVIDADES EXTENUANTES (tais como ter de se apressar, fazer ginástica, correr pela escada acima, praticar desporto)	1	2	3	4	5	6	7
13. ACTIVIDADES MODERADAS (tais como andar a pé, fazer o trabalho doméstico, tratar do jardim ou do quintal, ir às compras, subir escadas)	1	2	3	4	5	6	7
14. ACTIVIDADES SOCIAIS (tais como falar, brincar com crianças ou pegá-las ao colo, visitar amigos ou família)	1	2	3	4	5	6	7
15. ACTIVIDADES RELACIONADAS COM A SUA PROFISSÃO (tarefas que tem de desempenhar no seu trabalho*)	1	2	3	4	5	6	7

**Se não está empregado/a nem trabalha por conta própria, estas serão as tarefas que tem de desempenhar a maior parte dos dias*

CODIFICAÇÃO DE DOMÍNIOS:
Sintomas: 1, 4, 6, 8, 10
Limitação de actividade: 12, 13, 14, 15
Função emocional: 3, 5, 9
Estímulos do ambiente: 2, 7, 11

Appendix 14 – Abstract presented in the WONCA Europe regional Conference in Amsterdam in 2004

PORTUGUESE FAMILY PHYSICIANS STUDY ASTHMA RELATED CONSULTATIONS TO THEIR PATIENTS IN 2000-02

J Correia-de-Sousa, M L Silva

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Type of Paper: oral presentation

Aims: To calculate the incidence rate for asthma, quantify and assess the consultations related with asthma and the medication used for the treatment and control of asthma.
Design: A cross-sectional study of asthma related consultations with patients from the family physicians' (FP) lists from the Portuguese Sentinel Network in 2000-02.
Results: The population under observation of the participating doctors lists was 329923 persons. 5997 asthma related consultations were reported, a rate of 18.2 / 1000 inhabitants; 58.3 % were female patients. There was some variability on the number of cases per participating FP. The mean age of patients was 50.28 ± 0.6, with a gender difference. There were 422 new reported cases; therefore an incidence rate of 127.9 / 100000 inhabitants was estimated. The highest incidence rate was in the age group 0-4 years and the lowest in the over 75. In 66.1% of the consultations there was a prescription renewal, in 26.4% a follow-up, in 19.6% an acute episode was reported and in 7% there was a new case. The top therapeutic groups prescribed were inhaled b-2 agonists and steroids.
Conclusion: There was some variability on the number of cases per FP. The monthly incidence variation could be explained by the consultation rate differences. Incidence rate was somewhat lower than data found in the literature.