Living with asthma in Sweden—the ALMA study

B. Ställberg, U. Nyström Kronander, P. Olsson, L. Gottberg, E. Rönmark, B. Lundbäck

Summary Background: Recently performed studies have found a number of limitations in the daily lives of asthmatics, and a large disparity between the perception of the sufferers and what health care professionals believe matters to asthmatics. Aim: What matters to Swedish asthma patients, what medicines do they use, and are they compliant with given prescriptions? A further aim was to compare perceptions about asthma and asthma management in asthmatics and among Swedish general practitioners (GP). Design: A structured telephone interview of a representative sample of Swedish asthmatics, and a mailed questionnaire survey among GPs from different parts of Sweden. Methods: Screening by telephone of a random sample of 10,350 subjects aged 18–45. Of those, 240 were subsequently selected for a detailed structured telephone interview about their asthma. A mailed structured questionnaire containing similar questions to those asked of the asthmatics was sent to 600 GPs, and 139 returned completed answers. Results: 16% of the asthmatics reported (asthma) symptoms occurring every day during the previous month. Nocturnal symptoms at least twice per week were reported by 19%. Both these were reported by considerably higher proportions of the asthmatics than the GPs had expected. A large majority classified their disease as mild or very mild, although great majority reported frequent symptoms. Activities or situations which caused symptoms of asthma often or "now and then" were physical exertion, 67%; bad weather, 59%; contact with animals/pets, 58%; and visits to cafes or restaurants, 36%; and several asthmatics avoided these activities due to their asthma. Conclusion: A great majority of asthmatics report a large number of symptoms and limitations in their daily living in proportions which were roughly expected by the GPs.

KEYWORDS
Asthma; Living restrictions; Symptoms; Medicines; Epidemiology

Introduction

The prevalence of asthma has increased worldwide during the last decades. Sweden is no exception. In spite of this, hospitalizations and
emergency visits due to asthma decreased considerably in Sweden, particularly during the 1980s.\(^7\) The decrease occurred parallel with or shortly after the introduction of inhaled corticosteroids.\(^8\) Nevertheless, asthma remains a major public health problem, a cause of sick days,\(^9\) involving considerable costs for society.\(^10,11\)

Despite the improved pharmaceutical treatment regimes, clinical as well as epidemiological studies clearly illustrate that patients with asthma still report a wide range of symptoms, demonstrate bronchial liability, and a low remission rate.\(^3\)–\(^6,12\) However, there is a lack of knowledge based on representative samples of subjects with asthma about the well-being of the asthmatics and their compliance with prescribed medicines. Further, a study performed by British general practitioners (GPs) found a disparity between the GPs' aim for the treatment, which was the absence of symptoms, whereas the patients aimed to be able to perform different activities they wanted to do, but were restricted due to asthma.\(^13\)

The recently performed British study, Asthma In Real Life (AIR study), showed a large disparity between the perceptions of the asthmatics and those of the health care professionals, further it showed that the patients with asthma suffered from more symptoms than was expected and had to avoid a number of normal activities because of their asthma.\(^14\) The same results were found in the AIR study performed by adult asthmatics (D. Price, unpublished data).

Today there is a lack of knowledge about these aspects in Sweden. Most asthmatics in Sweden are managed by GPs, of whom those with a special interest in asthma have taken the initiative to a study on how it is to live with asthma in Sweden. Specialists in respiratory medicine and nursing were invited to participate. The study aimed to assess what matters to Swedish asthma patients, their use of medicines and their compliance with given prescriptions. A further aim was to compare perceptions about asthma and asthma management in patients, with the GPs' perceptions of how asthma influences the life of asthmatics.

**Material and methods**

The ALMA study was carried out in the form of telephone interviews of 240 randomly selected young to middle-aged Swedish asthmatics from the whole country. The interviews were performed by the Swedish Institute of Public Opinion Research (SIFO), and they were conducted from November 2000 to February 2001. The patients' perceptions about their asthma were compared with those of Swedish GPs by using a mailed questionnaire containing similar questions. The study was approved by the ethical committee at the Medical Centre Hospital, University of Örebro.

**Identification of the study sample**

A random sample of 10,350 subjects aged 18-45 years were asked over the telephone by the Swedish Institute of Public Opinion Research (SIFO) whether they were willing to answer four screening questions about asthma. The questions aimed to identify a sample having current asthma. The questions were as follows:

(a) "Have you ever had asthma?", and
(b) "Have you been diagnosed as having asthma by a physician?". If "yes" to any of the two questions, two further questions were asked:
(c) "Have you had problems or symptoms of your asthma during the last 12 months?", and
(d) "Have you used asthma medicines during the last 12 months, regularly or as needed?".

Current asthma was defined by "yes" to either question (a) or (b), and to question (c) or (d). Thus 348 subjects were identified as having current asthma, which corresponds to 3.3% of those who agreed to answer the screening questions.

The subjects identified as having current asthma and agreeing a comprehensive structured interview about their asthma were interviewed on a later occasion. The interviews were conducted consecutively, 240 (61% women) subjects in total, while 108 (31%) declined to participate.

**Structured telephone interview**

The interview questions and alternative responses were designed by the research group (i.e. the authors). The screening questions for asthma (three out of four) were from the OLIN-studies questionnaire,\(^15\) which is frequently used in Sweden and neighbouring countries.\(^16\)–\(^20\) At the interview, the questions and alternative responses were read by the interviewer, one by one, without further explanations except for a repetition of the questions where necessary.

The interview consisted of 51 questions. It included questions about the frequency of symptoms common in asthma, such as cough, wheeze, dyspnea, and attacks of shortness of breath. The questionnaire also included a large number of questions about different activities which could
provoke asthmatic symptoms, and whether asthmatic sufferers avoided these activities. Examples of such questions were:

“Are you troubled by your asthma when running or hurrying for the bus or train?” and “Do you ever avoid running or hurrying for the bus or train in order not to be troubled with asthma?”

“Are you ever bothered by asthma when you visit cafés or restaurants?” and “Do you avoid visiting cafés or restaurants in order not to get trouble with asthma?”

Each question was followed by five answer alternatives; “often/frequently”, “now and then/occasionally”, “rarely”, “never”, or “the question is not relevant”. The asthmatics were also asked to mention three activities or situations, during days with symptoms, which they were forced to avoid because of asthma. They were further asked to classify the degree of severity of their asthma.

Another part of the questionnaire included questions about their present asthma therapy, which asthma medicines they used, and how often the medicines were taken. Further, the patients were asked about their compliance with their doctor’s prescription of asthma medicines, how often and where they had their controls or check-ups for asthma, use of peak flow meters, and the frequency of emergency visits.

The GPs’ questionnaire

A written questionnaire was mailed to 600 randomly selected Swedish GPs from the Swedish register of physicians about their apprehension of how asthmatics aged 18–45 years feel, report symptoms, follow prescriptions, and use medicines. Regarding symptoms and asthma in special circumstances and at different exposures, as well as alternative responses, the questions and answer alternatives were identical, or as similar as possible, to questions put to the asthmatics. Completed answers were received from 139 (65% men) GPs. The GPs were required to make assumptions as to how large proportion the asthmatics had chosen the different answer alternatives.

Analyses

The size of the samples was based on the assumption that at least 200 asthmatics and at least 100 GPs would participate, further, that a difference between answers given by the two groups of 10% in the prevalence of a certain symptom or condition affecting half the studied sample, represented statistical significance. The distribution of the percentage for each answer for the GPs is given as mean values, 95% CI for the mean, and median values. For comparison of the asthmatics’ and GPs’ opinions regarding ordered and dichotomous variables, the percentages given by a GP were multiplied to the values (0, 1, 2, 3, …) of the answers to give a score. These scores from the GPs were tested against the answers from the asthmatics with Mann–Whitney U-test. All tests were two-tailed and conducted at the 5% significance level.

When listing activities or situations the asthmatics had to avoid on days with symptoms, several activities were allowed to be reported by the asthmatics as well as when assumed by the GPs, why statistical comparison of the outcome patterns has not been made. The question about the worst things about living with asthma according to the asthmatics, and as assumed by the GPs, is presented similarly.

Results

Frequency of symptoms and avoidance of activities

The proportion of asthmatics reporting symptoms daily during the previous month was 16%, and at least once every week, 49%. These proportions were greater than the GPs had assumed, or 5% and 36%, respectively (Fig. 1), and the response patterns given by the asthmatics versus the GPs diverged significantly (P<0.001). The proportion of those having symptoms less than once per month was 34%. Nocturnal symptoms at least twice per week were reported by 19%, which was also higher than the GPs had expected, 11% (Fig. 2). Also the response patterns about nocturnal symptoms given

![Fig. 1 Frequency of symptoms, day or night, reported by the asthmatics, and assumed by the general practitioners, respectively.](image-url)
by the asthmatics versus the GPs diverged significantly \( (P<0.001) \).

The frequency of symptoms in defined circumstances or due to different exposures was commonly reported as similar by asthmatics to GPs’ assumptions (Table 1). How frequently the asthmatics avoided these activities was also examined. However, the GPs assumed that most of these activities were avoided more frequently than the asthmatics actually reported (Table 1).

When asking the asthmatics to mention three activities or situations they had to avoid on days with symptoms, 36% sports, 22% exposure to smoke or strong smelling scents, 19% contact with animals/pets, and 18% going outdoors (Fig. 3). When asked what the worst thing about having asthma was, 51% answered limitations of normal activities, 38% shortness of breath or tiredness, and 7% chronic disease or dependency on medicines (Fig. 4). The GPs’ assumptions of what activities or situations the asthmatics had to avoid and what the worst things about asthma were, diverged from the asthmatics’ responses (Figs. 3 and 4).

Overall assessment and degree of severity

The GPs believed that more than half of the asthmatics were almost or completely free from symptoms, while only 1% of the asthmatics claimed they were completely free from symptoms and 26% felt they were almost symptom-free (Table 2). The great majority, 59%, felt that they had symptoms “sometimes”. At the same time 68% of the asthmatics classified their asthma as mild or very mild, while the GPs’ corresponding assumption was 52%. The GPs believed that 19% of the asthmatics had classified their disease as severe or very severe, while only 6% of the asthmatics had judged their asthma as severe or very severe.

Contacts with health care

The three most common sites for asthma checks were GPs in 58% of cases, lung-, allergy-, or internal medicine specialists, 13%, and industrial physicians, 7%, while 14% reported that they did not have any controls. The sites for prescription of medicines for asthma were similar, and 68% of the asthmatics received their prescriptions from GPs (Fig. 5). Twelve per cent reported that they had visited a physician or an asthma nurse for their condition during the last month, 38% during the last 6 months, 55% during the last year, and 78% during the last 2 years. Twenty-two per cent either did not remember or had had their last visit more than 2 years ago. Unscheduled emergency visits for asthma were made by 14% during the last 6 months.

Use of medicines

Seventy-six per cent of the asthmatics claimed that they often followed the prescriptions of the doctors, while 40% of the GPs believed this was so. However, in response to another question, only 34% stated they regularly followed the prescriptions most days a week all year round.

During the previous 7 days, 50% of the asthmatics had used inhaled short-acting beta-agonists, 38% inhaled cortico steroids, 8% inhaled long-acting beta-agonists, and 2% inhaled combined long-acting beta-agonists and cortico steroids. Forty-three per cent used their inhaled short-acting beta-agonists once or more every day. One hundred and seventy-nine (75%) had been prescribed inhaled cortico steroids, but in this group only 27% used these medicines as often as prescribed, 26% followed the prescription of inhaled cortico steroids “now and then”, 12% only rarely, and 35% never, while the GPs believed the compliance with inhaled cortico steroid treatment was greater.

Of the asthmatics, 19% had, at some time during the last year, not gone to pharmacies to get their medicines because of high costs, while 6% had not done so because of anxiety about side-effects. The corresponding figures for what the GPs believed were 26% and 17%.

Action at exacerbations or increase of asthma

The proportion of the asthmatics who claimed that they knew how to take their medicines if the asthma got worse was 95%, and 90% reported that their doctor had told them how to use the medicines in such circumstances. During periods of increased asthma activity, 88% reported
Table 1  Frequency of symptoms in defined circumstances or due to different exposures, and avoidance of these situations, reported by the asthmatics and assumed by the general practitioners. Difference in P-value by groups.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Frequency</th>
<th>Symptoms in situation</th>
<th>Avoidance of situation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Patients, n = 240</td>
<td>GPs, n = 139</td>
</tr>
<tr>
<td></td>
<td></td>
<td>% (CI95%) Mean (CI95%), median</td>
<td>% (CI95%) Mean (CI95%), median</td>
</tr>
<tr>
<td>Physical activity</td>
<td>Oft</td>
<td>28 (23–35) 27 (24–31), 20</td>
<td>18 (13–23) 26 (23–39), 20</td>
</tr>
<tr>
<td></td>
<td>Now and then 38 (31–44) 27 (25–29), 25</td>
<td>23 (18–29) 26 (24–29), 25</td>
<td>0.001</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>20 (15–25) 24 (21–26), 20</td>
<td>10 (6–14) 24 (21–27), 20</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>14 (9–18) 22 (19–25), 20</td>
<td>49 (43–56) 24 (21–28), 20</td>
</tr>
<tr>
<td>Physical activity in cold weather</td>
<td>Oft</td>
<td>33 (27–39) 31 (27–34), 35</td>
<td>21 (16–26) 30 (26–33), 25</td>
</tr>
<tr>
<td></td>
<td>Now and then 28 (23–34) 27 (25–29), 30</td>
<td>18 (13–23) 27 (25–30), 25</td>
<td>0.001</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>14 (9–18) 23 (20–25), 20</td>
<td>9 (6–13) 22 (20–25), 20</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>24 (19–30) 20 (17–23), 20</td>
<td>52 (45–58) 20 (17–24), 10</td>
</tr>
<tr>
<td>Running or hurrying</td>
<td>Oft</td>
<td>21 (16–26) 21 (18–25), 20</td>
<td>24 (19–30) 26 (22–30), 20</td>
</tr>
<tr>
<td></td>
<td>Now and then 34 (28–40) 31 (28–34), 30</td>
<td>16 (12–21) 24 (21–27), 20</td>
<td>0.150</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>27 (21–33) 27 (24–30), 20</td>
<td>14 (9–18) 26 (23–29), 25</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>18 (13–23) 20 (16–24), 10</td>
<td>45 (39–52) 23 (19–27), 15</td>
</tr>
<tr>
<td>Visiting cafés or Restaurants</td>
<td>Oft</td>
<td>13 (9–18) 27 (24–31), 20</td>
<td>9 (5–13) 22 (19–25), 20</td>
</tr>
<tr>
<td></td>
<td>Now and then 23 (18–28) 27 (24–29), 25</td>
<td>14 (9–18) 25 (21–27), 20</td>
<td>0.150</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>16 (12–21) 22 (19–25), 20</td>
<td>8 (4–11) 26 (22–29), 20</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>48 (41–54) 24 (20–28), 20</td>
<td>70 (64–75) 28 (24–33), 20</td>
</tr>
<tr>
<td>Exposed to animals/pets</td>
<td>Oft</td>
<td>36 (30–42) 28 (25–31), 20</td>
<td>33 (27–39) 35 (31–39), 30</td>
</tr>
<tr>
<td></td>
<td>Now and then 22 (16–27) 25 (23–27), 20</td>
<td>18 (13–23) 22 (20–24), 20</td>
<td>0.150</td>
</tr>
<tr>
<td></td>
<td>Rarely</td>
<td>14 (10–19) 21 (19–23), 20</td>
<td>7 (4–10) 19 (16–21), 15</td>
</tr>
<tr>
<td></td>
<td>Never</td>
<td>28 (22–34) 26 (22–29), 20</td>
<td>42 (36–49) 24 (21–28), 20</td>
</tr>
</tbody>
</table>
increased use of inhaled short-acting beta-agonists, 48% increased their use of, or started to use, inhaled corticosteroids, and 8% used oral corticosteroids. Situations in which the patients increased their medication were infections, during the pollen season, and at times of physical exertion.

Other findings
Almost daily use of peak flow meter was reported by 2%, use “now and then” by 10%, rarely by 14%, and no use at all by 74%. The corresponding figures for how frequently the GPs believed that asthmatics used the peak flow meters were 6%, 24%, 35%, and 35%, respectively. The answer patterns differ significantly ($P < 0.001$).

Of the 240 asthmatics, 31% were current smokers, while this proportion was expected by the GPs to be 21%.

Discussion
The main result of the study is that the asthmatics showed considerably more symptoms of asthma than expected, particularly symptoms in situations common in daily life. One out of six reported symptoms at least once every day, and a half reported symptoms at least once every week, both significantly higher values than the physicians had expected. Surprisingly many, almost one out of five, had nocturnal symptoms at least twice a week, which also was more frequent than the physicians had expected. These results confirm what other European studies have found. In the AIRE study, half of the adults reported daytime symptoms at least once a week and one-third reported sleep disturbance at least once a week. However, prescriptions of asthma medicines are...
common in Sweden, particularly in relation to the prevalence of respiratory symptoms, so the high proportion of the asthmatics having frequent symptoms was at least in part unexpected.

As predicted by the physicians, a majority of asthmatics displayed symptoms when performing different physical activities. Also when exposed to pets/animals, a majority experienced asthma symptoms often or frequently. Despite the frequency of symptoms when performing different activities, a majority only rarely, or never, avoided participating in e.g. visiting restaurants. The physicians had expected a greater proportion of the asthmatics to avoid such activities. Further, despite the frequency of symptoms, two-thirds of the asthmatics classified their asthma as either mild or very mild. This classification of asthma severity is about the same as in the AIRE study. This discrepancy suggests that asthmatics have adapted to living their lives without becoming symptom-free.

The assumptions of the physicians conformed surprisingly well to the answers given by the asthmatics. These results are in contrast to similar studies. Generally, the physicians had expected asthmatics to have fewer symptoms than those actually reported, but on the other hand, they believed asthmatics avoided different activities more frequently than they really did. This marks a departure from previous findings.

How valid are the results? One advantage is that both asthmatics and GPs were recruited from the whole country. The study aimed at recruiting a sufficiently large sample of subjects representative of asthmatics in society. The asthmatics were recruited by telephone interview performed by

### Table 2

Overall assessment of frequency of symptoms and degree of severity in the asthmatics' own judgment and according to how general practitioners believed the asthmatics would assess. Difference, P-value, between the groups.

<table>
<thead>
<tr>
<th></th>
<th>Patients, n = 240</th>
<th>GPs, n = 139</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Overall assessment of frequency of symptoms</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Always</td>
<td>4 (2.7)</td>
<td>7 (6.8), 20</td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td>14 (9.18)</td>
<td>15 (13.16), 30</td>
<td></td>
</tr>
<tr>
<td>Sometimes</td>
<td>59 (53.65)</td>
<td>25 (22.27), 20</td>
<td></td>
</tr>
<tr>
<td>Almost free from symptoms</td>
<td>26 (20.31)</td>
<td>30 (27.32), 15</td>
<td></td>
</tr>
<tr>
<td>Completely free from symptoms</td>
<td>1 (0.3)</td>
<td>24 (20.27), 5</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td><strong>Degree of severity of asthma</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very severe</td>
<td>1 (0.2)</td>
<td>7 (6.8), 5</td>
<td></td>
</tr>
<tr>
<td>Severe</td>
<td>5 (2.8)</td>
<td>12 (11.13), 10</td>
<td></td>
</tr>
<tr>
<td>Moderate</td>
<td>26 (20.31)</td>
<td>29 (27.32), 27</td>
<td></td>
</tr>
<tr>
<td>Mild</td>
<td>48 (42.55)</td>
<td>31 (29.34), 30</td>
<td></td>
</tr>
<tr>
<td>Very mild</td>
<td>20 (15.25)</td>
<td>21 (19.23), 20</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>

Fig. 5 Sites for asthma controls and prescriptions of medicines, reported by the asthmatics.
an investigation group performing all kinds of interviews on a wide range of topics. The number of asthmatics not wishing to participate was 31%, which may have influenced how representative the sample was. The non-participation rate must be judged as somewhat high when compared to results from Swedish epidemiological studies of asthma based on the general population.\textsuperscript{6,15,16,24,25} Moreover, the total prevalence of asthma according to the interview is lower compared with results from prevalence studies using postal questionnaires.\textsuperscript{6,15,16,24} Asthmatics may also have avoided admitting they had asthma as a question of integrity, or in order to avoid participating in a time-consuming interview performed by persons not involved in health care. Possible bias may therefore have resulted in mainly randomly occurring errors with an influence, albeit limited, on the results. The results of this study point in the same direction as the European study, AIRE, with frequent daytime symptoms but also night-time symptoms.\textsuperscript{21} The AIRE study was also performed by telephone interviews and yielded a somewhat lower prevalence of asthma compared with postal questionnaire surveys. On the other hand, asthmatics with more symptoms may have been more likely to participate compared with asthmatics with mild intermittent asthma. If so, bias of that kind would have caused a systematic error in the sense that asthmatics with milder symptoms would have been somewhat underrepresented in the study.

Do the GPs who participated in the study reflect GPs in general? The age and gender distribution of the GPs suggests that this is the case, although the participation rate has to be considered low. A possible explanation for the relatively close correlation between the GPs’ opinion and the answers given by the asthmatics may be that the GPs who participated have a special interest in asthma care and treatment. If those who are not very interested in asthma did not participate, we can assume that the GPs’ opinions about the asthmatics’ problems and well-being could differ from those of GPs in general. We have to keep in mind that almost half of the subjects had not visited any health care institution on the grounds of their asthma during the previous year.

Another important finding was that the asthmatics felt they complied well with prescriptions made by the physicians, even though a large discrepancy was found between the prescriptions and the actual use of medicines. The compliance with regular medicine use was low, findings which agree with others.\textsuperscript{26,27} Particularly low was the use of inhaled cortico steroids, a result that surprised us. Increased asthma activity was treated by the patients in a similar way to that described in other studies,\textsuperscript{21,23,28} i.e. they increased mainly the use of inhaled beta-agonists that work in the short term. However, a majority of asthmatics with inhaled cortico steroids increased their use, or started to use them, during periods with increased asthma activity.

Other interesting findings were that only a small proportion of the asthmatics used peak flow meters, confirming results found by others.\textsuperscript{21} In Sweden 19\% of the adult population are current smokers,\textsuperscript{29} but 31\% of the asthmatics in our study were current smokers!

In the UK the question was raised whether physicians did not ask the right questions when they met the patients.\textsuperscript{13,14} In our study, the assumptions made by the physicians reflected the picture given by the asthmatics themselves generally well. One question that emerges from our results is why such a small proportion of the asthmatics are free from symptoms. Do the real aims of treatment differ from those set out in guidelines? Is the aim of treatment for asthmatics in reality too low? Or is the main point that the resources available for the health care of asthmatics are too limited, or the costs of medicines too high? Only a low proportion of asthmatics was afraid of side-effects from the medicines.

We have to keep in mind that asthmatics very often make their own decisions not to use their medicines, even if they have the opportunity. Thus, another question is whether the treatment regimes are too complicated?

In conclusion, Swedish GPs have a fair and often good knowledge about the well-being of asthma sufferers. In spite of this, a large number of Swedish asthmatics show frequent symptoms and experience restrictions in their daily lives. A surprisingly large proportion reported nocturnal symptoms.

Acknowledgements

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References

Living with asthma


