Patient preferences for autonomy in decision making in asthma management

R J Adams, B J Smith, R E Ruffin

Abstract

Background—Lower patient preferences for autonomy in management decision making during asthma exacerbations have been associated with an increased risk for future hospital admissions. We sought to examine patient preferences for asthma self-management autonomy, and the clinical and psychosocial factors associated with autonomy preferences.

Methods—A cross sectional observational study was performed with data collected between June 1995 and December 1997 of 212 adult patients with moderate to severe asthma managed, at least in part, at two teaching hospitals. Subjects completed a survey of autonomy preferences, quality of life, clinical morbidity and health service use, asthma knowledge, self-efficacy, coping styles, and psychosocial measures.

Results—Patients preferred clinicians to assume the major role in most decision making about their management. However, patients wished to remain in control in choosing when to seek care and wanted to share decisions regarding initiating changes in medications during a moderate exacerbation. Multiple regression analysis showed that concerns about adverse effects of medications, education level, an active coping style, perceptions of the propensity of physicians to involve them in treatment decision making, and concerns about costs causing delays in seeking medical care were associated with preferences for autonomy in decision making. Autonomy preferences were not related to measures of concurrent clinical asthma control or health related quality of life.

Conclusions—In a group of patients with moderate to severe asthma, a high proportion of whom were from socioeconomically disadvantaged backgrounds, education level, perceived physician behaviour, cost barriers to care, and psychosocial factors (but not clinical asthma control or management) were related to patient preferences for autonomy in management decision making during asthma exacerbations. This has implications for asthma action plans and design of self-management programmes.

Keywords: asthma; self-management; decision making; patient preference
encouraging self-control over treatment may not be universally appropriate.

Using the Asthma Autonomy Preference Index (API), we have examined the issue of patient preferences for asthma self-management autonomy in a group with moderate to severe asthma. We have investigated the relationship between autonomy preferences and a number of clinical and psychosocial measures as well as sociodemographic characteristics. We have also looked at the effect on autonomy preferences of patients’ perceptions of the extent to which their physicians seek to involve them in decision making about treatment.

**Methods**

**Protocol**
The data for this study came from patients participating in the Western Region Asthma Pilot Project (WRAPP), a longitudinal observational study of factors related to asthma outcomes in adult hospital based patients over a 12 month follow up period. The study methodology has been described previously. Data were collected between June 1995 and December 1997 from subjects attending two teaching hospitals in Adelaide, South Australia (population 1.2 million) for at least part of their asthma management. Consecutive adult subjects were recruited following attendances at either site in outpatient clinics and emergency departments, or hospital admissions for asthma. Subjects were eligible if they had a physician’s diagnosis of asthma together with evidence of an increase of at least 15% in forced expiratory volume in one second (FEV₁) after administration of bronchodilator medication or evidence of bronchial hyperresponsiveness with a histamine challenge test. Informed consent was obtained from all subjects. Following enrolment, surveys were sent by post every three months to all subjects for self-administration. As we wanted to examine the effect on patient preferences following at least 12 months’ contact with the two hospitals, the analysis presented here is a cross sectional study from the 12 month follow up survey only. However, similar results were obtained for the other study periods.

**Autonomy Preference Index (API)**
The asthma API was adapted by Gibson and colleagues from the API scale of Ende et al. It was designed to measure preferences for autonomy in decision making in a general sense, as well as the extent to which people prefer doctors or themselves to make specific management decisions in three clearly defined asthma clinical vignettes. These hypothetical situations correspond to a routine office visit for stable disease (“Stable”), an attack of moderate severity requiring increased medications and an unscheduled physician visit (“Moderate” attack), and a severe episode requiring hospitalisation and an admission to an intensive care unit (“Severe” attack). Responses to the asthma API are made using a five point Likert-type response scale ranging from “definitely yes” to “definitely no” for item (1) and from “very often” to “not at all” for item (2) and from “definitely yes” to “definitely no” for item (3). Variations in PDM style were scored according to the methods of Kaplan et al.

**Physician’s Participatory Decision Making (PDM) Style**
Patient perception of the physician’s PDM style was assessed as the aggregate of the following three questions: (1) “If there were a choice between treatments, would your doctor ask you to help him/her to make the decision?” (2) “How often does your doctor make an effort to give you some control over your treatment?” and (3) “How often does your doctor ask you to take some of the responsibility for your treatment?” Responses were given on a five point Likert-type response scale ranging from “definitely yes” to “definitely no” for item (1) and from “very often” to “not at all” for items (2) and (3). Variations in PDM style were scored according to the methods of Kaplan et al.

**Psychosocial Characteristics**
A number of validated scales were used to measure different psychosocial characteristics of importance in asthma. Personal coping styles thought to be of importance in asthma were measured— including denial, active, and avoidance coping. Active coping strategies measured were predominantly behavioural—

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Table 1  Sociodemographic data of the study population (n=212)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>15–34 years</td>
<td>42</td>
</tr>
<tr>
<td></td>
<td>35–44 years</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>45–64 years</td>
<td>17</td>
</tr>
<tr>
<td></td>
<td>&gt;65 years</td>
<td>13</td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>33</td>
</tr>
<tr>
<td>Marital status</td>
<td>Married</td>
<td>61</td>
</tr>
<tr>
<td></td>
<td>Divorced</td>
<td>39</td>
</tr>
<tr>
<td>Country of birth</td>
<td>Australia (non-Aboriginal)</td>
<td>64</td>
</tr>
<tr>
<td></td>
<td>Australia (Aboriginal)</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>34</td>
</tr>
<tr>
<td>Annual income level (% A$)</td>
<td>&lt;A$8000</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>A$8000–20000</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>A$20001–50000</td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>&gt;A$50000</td>
<td>8</td>
</tr>
<tr>
<td>Principal income source (%)</td>
<td>Wages/salary</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>Government</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>Pensions/allowances</td>
<td>54</td>
</tr>
<tr>
<td>Education level</td>
<td>≤10 years school</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>&gt;10 years school</td>
<td>26</td>
</tr>
<tr>
<td></td>
<td>Some post school</td>
<td>28</td>
</tr>
<tr>
<td>Employed (%)</td>
<td>Yes</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td>No/retired</td>
<td>54</td>
</tr>
</tbody>
</table>

Table 2  Asthma management and morbidity among the study population (n=212)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Category</th>
<th>% population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current asthma status</td>
<td>Moderate</td>
<td>45</td>
</tr>
<tr>
<td></td>
<td>Severe</td>
<td>55</td>
</tr>
<tr>
<td>FEV1 (% predicted)</td>
<td>&lt;80%</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>60–80%</td>
<td>39</td>
</tr>
<tr>
<td></td>
<td>&gt;80%</td>
<td>32</td>
</tr>
<tr>
<td>Inhaled corticosteroid dose (µg/day)</td>
<td>0</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>1–1000</td>
<td>29</td>
</tr>
<tr>
<td></td>
<td>1001–2000</td>
<td>32</td>
</tr>
<tr>
<td></td>
<td>&gt;2000</td>
<td>19</td>
</tr>
<tr>
<td>Regular oral corticosteroids</td>
<td>Yes</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>&gt;Weekly but &lt;daily</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>1–4 times/day</td>
<td>28</td>
</tr>
<tr>
<td></td>
<td>&gt;4 times/day</td>
<td>22</td>
</tr>
<tr>
<td>Bronchodilator use</td>
<td>Yes</td>
<td>55</td>
</tr>
<tr>
<td>Possess written asthma action plan</td>
<td>Yes</td>
<td>55</td>
</tr>
</tbody>
</table>

FEV1 = forced expiratory volume in one second.

STATISTICAL ANALYSIS

Comparisons between each of the scenarios were made by means of analysis of variance (ANOVA). Internal consistency of the scales was assessed by Cronbach’s alpha coefficient. Relationships between scales and with other variables were assessed using Pearson’s product moment correlation for continuous variables and intraclass correlation for categorical variables. Given the large number of variables available for analysis, significance at the p<0.10 level provided the basis for inclusion of variables into multivariate models in a parsimonious manner. To assess which variables were the most important predictors of decision making autonomy preferences, multiple linear regression analyses for the overall asthma API were conducted. The Moderate attack scenario closely resembles the situation usually addressed by current written asthma action plans, requiring a patient to make decisions in response to increased symptoms regarding initiating changes in medications and about when to seek medical care. To investigate whether different independent variables predicted preferences in Moderate attacks compared with the overall autonomy index, models were also developed for the Moderate attack scenario and for the rest of the index scores without the items from this section included. All variables found to be significant at the univariate stage were entered into the regression models. Insignificant variables were progressively omitted until satisfactory models were found. The models were examined for goodness of fit.

Asthma control was estimated by grouping subjects into categories of severity defined by the NAEPP. Use of asthma medication was estimated by use of inhaled corticosteroids, regular oral corticosteroids, bronchodilators, and other asthma medications such as salmeterol and theophylline. The groupings used for these variables correspond to the parameters shown in table 2.

Approval of the study protocol was obtained from the ethics committees of both institutions.

Results

Of 343 individuals identified as eligible for enrolment, completed survey responses were received from 293 at baseline and 212 (72% of responders) completed the 12 month surveys and were included in this analysis. Most of the 61 subjects lost to follow up declined to participate further in the study. There were no statistically significant differences for the groups with and without 12 month follow up when compared for age, sex, education, household income, baseline asthma status, medication use, or lung function. There were no significant differences between the eligible group who did not return baseline surveys and the study subjects when compared for age, sex, or lung function.

The sociodemographic and clinical characteristics of the study population are shown in tables 1 and 2. The mean (SD) age was 41 (19) years. All subjects currently had moderate or severe persistent asthma according to the criteria of the NAEPP. These patients reported using relatively intensive medication regimens compared with those described in community surveys. There was a relatively low level of formal education compared with that in the Australian population as a whole. There was also a relatively high proportion of income assistance with 54% receiving some form of government pensions or allowances compared with a national figure of 30%. Over half (57%) reported having financial difficulties over the past year, and 40% indicated that concerns about costs had caused them to delay or avoid seeking care needed for their asthma in the previous 12 months.
Table 3 Mean (SD) asthma autonomy preference index (API) scores* (n=212)

<table>
<thead>
<tr>
<th>Asthma API</th>
<th>Cronbach alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable follow up</td>
<td>3.4 (0.8)</td>
</tr>
<tr>
<td>Moderate attack</td>
<td>3.1 (0.9)</td>
</tr>
<tr>
<td>Severe attack</td>
<td>3.9 (0.9)</td>
</tr>
<tr>
<td>General autonomy</td>
<td>3.3 (0.8)</td>
</tr>
<tr>
<td>Total asthma API</td>
<td>3.4 (0.8)</td>
</tr>
</tbody>
</table>

*Maximum 5 = "Doctor alone should make decisions"; minimum 1 = "Patient alone should make decisions".

**Asthma API scores**

The mean scores for each exacerbation scenario, the general autonomy items, and the overall preference index are shown in table 3. Each mean scale score indicated a tendency for patients to prefer clinicians to assume the major role in decision making. For Total autonomy only 37% of subjects indicated a preference for greater input than their physicians into treatment decisions. For Total autonomy only 37% of subjects indicated a preference for greater input than their physicians into making decisions (score of <3.0). All three items dealt with decisions concerning the timing and necessity of physician visits. Autonomy preferences were stable over 12 months with minimal score changes seen in any of the categories, and with intraclass correlation coefficients of 0.82–0.88 for the different scales.

Overall, patients expressed significantly stronger preferences for self-management autonomy in the Moderate scenario than during a routine visit for stable disease or a more severe attack (p<0.001). In the Moderate situation 64% of subjects indicated a preference for more input than their physicians into management decisions. However, when these scenario items were considered individually, there was a stronger preference for autonomy about when to see a physician than for decisions regarding altering medications. There was a significant difference (p<0.01) between scores for the item regarding who should decide whether a visit to see a physician was needed (2.0 (0.9)) compared with whether an increase in asthma controller therapy was needed (3.4 (1.0)) or whether oral corticosteroids were indicated (3.5 (1.0)). During a Severe attack requiring admission to hospital significantly weaker preferences for autonomy compared with the other scenarios were reported (p<0.0001). However, 26% of patients scored below 3, indicating a desire for equal or greater participation than physicians in decision making even during a severe attack necessitating admission to an intensive care unit.

**Univariate analysis**

A number of variables were significantly associated with Total asthma API scores in univariate analysis (p<0.01). Stronger preferences for decision making (Total) were associated with more education (r = 0.32), more concerns about adverse effects of medications (r = 0.40), use of more active coping strategies (r = 0.30), a more positive evaluation of the impact of asthma on their lives (satisfaction with illness) (r = 0.24), greater self-efficacy in asthma management (r = 0.29), and patients’ perceptions of the physicians’ propensity to involve them in decision making (physician’s PDM style) (r = 0.29). These variables were also significantly associated with scores in a Moderate attack. There was also an association seen with age, younger patients expressing a greater desire for self-management autonomy (p=0.01). In addition, possession of a written asthma action plan showed a significant positive association with higher autonomy preferences in a Moderate attack (p=0.008). There were no significant associations with any indicators of clinical status or quality of life and any of the attack scenarios, or for the overall index.

**Multivariate models of decision making preferences**

Multiple regression analysis showed that concerns about the adverse effects of medications, active coping strategies, perception of the physicians’ PDM style, cost concerns that caused delays in seeking care, and education level were significantly associated with preferences for autonomy in decision making with regard to asthma management, adjusting for age (table 4). The model was able to explain 48% of the variance.

The model for the index minus the Moderate scores was not significantly altered from the original overall model. In the Moderate attack model education level was not significantly associated with preferences for control over decisions. The other variables identified in the Total autonomy model remained significantly associated, and this model could explain 42% of the variance. Possession of a written action plan or a history of previous hospital admissions did not contribute to the final model.

**Discussion**

The results of this study in patients with moderate to severe asthma from a diverse range of sociodemographic backgrounds indicate that, on average, individuals in this at-risk group do not desire to be predominantly responsible for decisions regarding asthma management. These findings are similar to those found by Gibson et al who studied both community asthma sufferers and those following a recent hospital admission. Multivariate analysis showed that autonomy preferences were associated with patient characteristics such as attitudes regarding adverse effects of medication, active coping mechanisms for dealing with asthma, cost concerns, and the level of...
formal education. Aspects of the patient-doctor interaction—specifically, the extent to which patients perceive that their doctors seek to involve them in decision making—also showed a significant association with autonomy preferences. Possession of a written action plan was not associated in the multivariate analysis with autonomy preferences in the Moderate attack, which is the vignette that corresponds to their use.

Asthma management decisions can be complex and it is impossible to codify every contingency that patients might face in managing their asthma. The objectives of asthma management are the acquisition of sufficient knowledge to make sense of changing symptoms and lung function, together with the knowledge to make sense of changing symptoms in what may be regarded by clinicians as a relatively straightforward medical situation. Given the nature of the questions asked in this scenario, it is possible that these items may, for some people, be just inquiries of their perceived ability to afford the cost of the medicine. It would seem unlikely that patients will enthusiastically initiate increases in medications or seek medical advice if the cost implications of these actions weigh heavily in their assessment. The predominance of cost concerns over perceived financial difficulties on autonomy preferences may relate to differences in the priorities of some patients who have to make choices about spending options. The issue of whether there are other non-financial barriers to care was not explored in this study, and the potential influence on preferences for decision making autonomy of these factors is an area for future examination.

Individuals who expressed strong concerns about the adverse effects of medications also desired retaining autonomy over decision making. These patients also said that concerns about side effects stop them taking many asthma medications. Our data do not show whether the concerns held by patients were erroneous or unwarranted fears, or if they arose out of previous adverse experiences. From the perspective of pragmatically attempting to enhance appropriate self-management in exacerbations, whether these fears are unwarranted or not is less important than the realisation by www.thoraxjnl.com

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clinicians that real fears exist and have a major influence on attitudes and behaviour in asthma management.

Interventions that encourage patients to negotiate treatment decisions with their doctor show improved outcomes in some chronic conditions. A positive doctor-patient interaction has beneficial effects on patient adherence and behaviour in asthma. Our results suggest a critical role for the attitude and behaviour of the doctor in fostering decision making independence. Proven techniques exist to improve communication, patient education, and involvement. The integration of these techniques into an intervention directed towards children with asthma has been associated with improved outcomes, including reduced hospital admissions. Although the measure of PDM style was based on patient report only, and not on observation of physicians, it can be argued that the perception of the patient is ultimately the only criterion by which the physician’s efforts in this area can usefully be judged. Given that a large proportion of the variance in autonomy preferences was not explained by the wide range of variables considered here, it would seem that the only way a clinician can ascertain an individual’s desire for involvement in decision making is by some form of direct inquiry. This may require a definite change in current practice, as eliciting patients’ preferences and level of understanding are reported to be rare components of patient-physician discussions in primary care.

The nature of the study sample, with all subjects having moderate to severe asthma, may limit the generalisability of these results. It is possible that a community sample with less severe asthma may express different levels of self-management autonomy preferences, although this was not found by Gibson et al. A recent representative population survey in the US found that up to two fifths of all adults with a physician’s diagnosis of asthma had symptoms at a similar level as the subjects in this study. In addition, individuals with socio-economic disadvantage may have different attitudes from those with higher socioeconomic status. Although the sample had a higher proportion of people with lower income and education than the general population, it was still diverse in terms of all the socio-demographic variables assessed. While acknowledging these limitations, a number of studies have shown that socioeconomically disadvantaged groups are at risk for adverse asthma outcomes, and hence ascertaining factors that influence acceptance of autonomy in self-management programmes in these people is important. It is possible that lower education may produce difficulties in responding to the questionnaires and produce biased results. However, there were no difficulties noted during the survey period, and the internal consistency measures did not suggest inconsistent patterns of responses as might be expected if there were major problems.

There seems little reason to suppose that an extreme “consumerist” approach to health care is favoured by many patients with moderate to severe asthma. It appears that an approach that deals with self-management individually and in partnership with physicians is the preferred option for most patients and has the most chance of success. In the self-management of asthma the issue of how much autonomy patients want in decision making and how this is best accommodated will need to be directly addressed. The difficulty is that this will be demanding of both the time and the emotional and clinical resources of the attending clinicians.

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