Survey of patients’ views of domiciliary nebuliser treatment for chronic lung disease

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Abstract

There is some controversy amongst respiratory physicians over the value of domiciliary nebuliser use for chronic lung conditions. Most recommendations for assessment of suitability for this form of treatment rely upon response to lung function tests and reported improvements in exercise ability. Relatively little emphasis has been placed upon the patient view of this therapy. This survey examined the subjective views of patients receiving domiciliary nebulisers regarding this treatment. A postal questionnaire was sent to 82 patients using home nebuliser treatment provided by the respiratory clinic at Whipps Cross University Hospital, London. It consisted of 29 structured questions covering topics of well-being and symptom control, self-confidence, dependency, time and technical issues, as well as side effects and compliance. Most patients surveyed had chronic obstructive lung disease. For almost all sections of the questionnaire patients reported overwhelmingly that the benefits of using an nebuliser outweighed potential disadvantages. The main perceived advantages were the ability for patients themselves to control symptoms and to be less dependent on General Practitioners, hospitals and carers. Compliance was generally excellent, and the reported side effects were minor and relatively infrequent. The results strongly support the view that nebulisers are helpful in managing chronic lung disease in the community, with benefit to patient well-being and potential health cost savings.

INTRODUCTION

The prescription of domiciliary nebuliser treatment for chronic obstructive pulmonary disease (COPD) is a controversial medical intervention. It is a relatively expensive treatment (1,2) and it requires a designated support service to ensure appropriate usage and to maintain and replace the equipment (3–6). The objective clinical efficacy of nebulised bronchodilators in COPD remains questionable. Previous studies have shown a lack of improvement of lung function tests for many patients (7–9) and have failed to provide evidence that domiciliary nebuliser treatment reduces admissions to hospitals or shortens hospital length of stay (10).

Despite this evidence nebulisers are widely prescribed for the long-term treatment of COPD in the community. One important reason for the continuing high level of use in the community is the subjective benefit many patients appear to experience while using nebulisers at home. Some studies have confirmed an increased quality of life for users of domiciliary nebulisers, with many patients reporting that they feel less breathless (10–13). In contrast regular use of high-dose bronchodilating agents produce side effects such as intolerable tremor, tachycardia and even cardiac arrhythmias that may offset the quality of life improvements from bronchodilation (14).

It is the patient that often demands a nebuliser and then asks to continue with the therapy; yet, to our knowledge, no study has specifically explored the reasons for this and patients’ own attitudes to the long-term use of nebulisers for the treatment of COPD. This study attempts to address this issue with particular reference to the perceived benefits and disadvantages of long-term nebuliser use in such patients.
PATIENTS AND METHODS

A detailed postal questionnaire was sent to all 82 patients who were receiving home nebuliser treatment provided by the respiratory clinic at Whipps Cross University Hospital, London, U.K. Patients who failed to return the questionnaire were then reminded to complete the form by a phone call from the nurse specialist.

All the patients had previously undergone a detailed assessment for their suitability for treatment as suggested by the British Thoracic Society guidelines published in 1997 (15). A dedicated service led by a specialist respiratory nurse based at the Chest Clinic supports the patients and monitors servicing and maintenance of their technical equipment.

The first part of the questionnaire consisted of 24 questions following a scaling system suggested by Hyland et al. (16). This system assigns the following scores to the individual responses: ‘strongly agree’ (5), ‘agree’ (4), ‘not sure’ (3), ‘disagree’ (2) and ‘strongly disagree’ (1). The questionnaire was composed of questions included on the grounds of medical importance and from ideas generated by a local patient support group (Waltham Forest Breathe Easy) as relevant to their quality of life sufferers from chronic lung disease. Questions were grouped into the following categories: (A) well-being and symptom control, (B) self-confidence, (C) dependency, (D) time issues, (E) technical issues, and (F) General impressions. Thirteen of the questions related to the possible advantages to be gained by use of home nebulisers; the other 11 questions concerned the possible disadvantages of the treatment.

Generally, a response was counted as positive, when the question was answered with ‘strongly agree’ or ‘agree’. It was counted as negative, if the answer was ‘disagree’ (2) or ‘strongly disagree’ as suggested by Hyland et al. (16) for easier data interpretation. For statistical analysis a Chi-square test was used (on Excel, Microsoft, U.S.A.)

A null-hypothesis was artificially constructed by assuming an equal number of answers accounting for a positive (‘strongly agree’ and ‘agree’, see above under Patients and Methods) and a negative response (‘strongly disagree’ and ‘disagree’, see above), thus implying that there would not be a statistically significant difference in the opinion of the group. This value was compared with the actual answers received. This way a Chi-square value was calculated. With a confidence interval of 95% all Chi-squares with a $P < 0.05$ are significant ($P < 0.01$ highly significant). A second part of the questionnaire consisting of four questions was designed to examine the compliance. Patients were asked the recommended frequency of usage when started with their treatment, how often they use it currently, and if there was a change made, who was responsible, and finally what the reasons for a change were when one was made.

With the last set of questions we wanted to find out about the possible side effects and the frequency of their occurrence (often, seldom, never).

RESULTS

Seventy five out of 82 patients returned the questionnaire providing a 91.5% response rate. The median age was 71.5 years (71.5 ± 8.6); 45.3% were female, 54.7% male. The median FEV1 was 40% (40 ± 15%) of predicted.

The drugs used for the nebuliser treatment were either salbutamol and/or ipratropium bromide. Thirty-two per cent used only a single drug, 56% both. Twelve per cent used additionally an inhaled glucocorticoid or normal saline.

Out of those 75 patients returning their questionnaire 57 (76%) had COPD, 6 (8%) suffered from asthma, 2 (3%) from bronchiectasis, 1 (1%) each accounted for allergic alveolitis and thoracoplasty post-surgery for tuberculosis. The diagnosis of 8 (11%) patients was unspecified (‘shortness of breath’).

Overall, patients reported overwhelmingly that the benefits of using a nebuliser at home far outweighed the disadvantages (98.2% vs. 1.8%).

The majority strongly agreed or agreed that using domiciliary nebulisers made a big difference to their life. The summarised results of the questionnaire are reported in Tables 1 and 2.

ADVANTAGES OF NEBULISER USE

The main advantages that were reported by a majority of patients can be categorised as (a) an increased feeling of personal well-being, (b) better symptom control, (c) an increased confidence and (d) the perception of greater independence. (For detailed results see also table I).

In category A the majority of the questioned patients felt that the nebulisers help them effectively to reduce the symptoms of their chronic respiratory disease. Most patients agreed that their chest felt more comfortable after using the nebuliser. Nearly, three quarters of the patients found the nebulisers superior to their inhalers in symptom relief. Breathing was commonly reported as much easier after using a nebuliser. More than half of the participants felt they could walk further following nebuliser treatment.

Most users of home nebulisers also felt more in control of their disease as reflected in the results of the category B questions:

Three-quarters agreed with the statement that the nebuliser treatment would keep them out of hospital. The majority also thought, their need for
Table 1. Advantages of nebuliser treatment

<table>
<thead>
<tr>
<th>Category A: well-being and symptom control</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Not sure</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Positive answers (% of total in brackets)</th>
<th>Negative answers (% of total in brackets)</th>
<th>Chi-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chest more comfortable</td>
<td>21</td>
<td>36</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>57 (76.0)</td>
<td>2 (1.8)</td>
<td>49.44</td>
</tr>
<tr>
<td>Helps breathing more than inhalers</td>
<td>22</td>
<td>31</td>
<td>11</td>
<td>3</td>
<td>2</td>
<td>53 (70.7)</td>
<td>5 (6.67)</td>
<td>39.72</td>
</tr>
<tr>
<td>Can walk further after nebulisers</td>
<td>13</td>
<td>29</td>
<td>16</td>
<td>12</td>
<td>0</td>
<td>42 (56.0)</td>
<td>12 (16.0)</td>
<td>16.67</td>
</tr>
<tr>
<td>Makes breathing easier</td>
<td>30</td>
<td>38</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>68 (90.7)</td>
<td>1 (1.3)</td>
<td>67.03</td>
</tr>
</tbody>
</table>

Table 2. Disadvantages of nebuliser treatment

<table>
<thead>
<tr>
<th>Category C: Dependency</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Not sure</th>
<th>Disagree</th>
<th>Strongly disagree</th>
<th>Positive answers (% of total in brackets)</th>
<th>Negative answers (% of total in brackets)</th>
<th>Chi-square</th>
</tr>
</thead>
<tbody>
<tr>
<td>Worry to become too dependent</td>
<td>16</td>
<td>19</td>
<td>12</td>
<td>20</td>
<td>4</td>
<td>35 (46.7)</td>
<td>24 (32.0)</td>
<td>1.7</td>
</tr>
<tr>
<td>Worry in case nebuliser brakes down</td>
<td>15</td>
<td>19</td>
<td>6</td>
<td>27</td>
<td>3</td>
<td>34 (45.3)</td>
<td>30 (40.0)</td>
<td>0.25</td>
</tr>
<tr>
<td>Feel totally dependent</td>
<td>9</td>
<td>15</td>
<td>23</td>
<td>18</td>
<td>2</td>
<td>24 (32.0)</td>
<td>20 (26.7)</td>
<td>0.36</td>
</tr>
</tbody>
</table>

Disadvantages of using home nebulisers categorised. The patients were confronted with a statement and had to decide whether to strongly agree, agree, being not sure, disagree or strongly disagree. Strongly agree and agree (5 and 4) were counted as positive response to a statement, disagree and strongly disagree (1 and 2) as negative response (see also Methods). The number of completed questionnaires was 75. Bold numbers show that the result is highly significant (P < 0.01). All results in this table are highly significant!
help by their family was less, and additionally they needed to call their GP less often for help than before. Patients felt much more in charge of their symptom control and that they could help themselves more once they used a nebuliser. This brought with it a general impression of greater independence.

**DISADVANTAGES (RESULTS SEE ALSO TABLE 2)**

Most respondents felt they would be lost without their nebulisers. This feeling promotes increasing dependence on their treatment (category C).

One-third felt totally dependent on their nebulisers. Nearly, half of the surveyed patients were worried that they would become too dependent on their nebulisers.

Although the time taken to nebulise medication is another potential drawback to this form of treatment few patients had the impression that their day revolved around the treatment.

Only one-third felt that the treatment took up a lot of time.

Problems with maintenance of the equipment or technical difficulties (category E) were identified as another, but only a minor disadvantage of home nebuliser treatment.

Most people did not experience any problems with keeping their equipment clean.

Half of the group thought the nebuliser machine to be too heavy to be carried around.

This could be a possible reason, why one-fifth of the patients felt restricted from going on holidays, although the majority was quite happy to go on holidays once in a while.

Few people felt restricted in going out during the day by the treatment. Some felt embarrassed when using their nebuliser in public.

**COMPLIANCE**

The next set of questions related to the compliance of patients with the frequency of use at home (see also Table 3a and b).

Changes in frequency were made in 40% of the cases. Fifty per cent of those changes were ordered by a healthcare worker (either hospital consultant, GP or Respiratory nurse), but in 50% users themselves initiated changes.

Interestingly, when a medical specialist felt a change was required, it was generally to an increase in use. If the patients made the change, the frequency was more often reduced than increased.

Reasons for any change (either increasing or decreasing the frequency) by the patient were a recent chest infection (10 patients), the impression that the treatment did not last long enough (4 patients) or did not really help (3 patients), the side effects, improvement of the condition, varying symptoms, fear of becoming too dependent, and that the treatment would absorb too much time (each of the last reasons had one quotation).

**SIDE EFFECTS (SEE ALSO FIG. 1)**

The side effect, experienced most, was a dry mouth. Forty-eight per cent of the patients had often a dry mouth after using the nebuliser.

The next commonest side effect was change in taste followed by tremor and palpitations. A rare side effect was angina. Only 13.5% experienced angina (5.3% often, 6.7% seldom, 53.3% never). More commonly people complained of chest tightness connected with nebuliser use: just 9.3% had often a tight chest after using their nebuliser, but 26.7% had this impression now and again (40.0% never).

<table>
<thead>
<tr>
<th>TABLES 3.</th>
<th>Compliance issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Data on how often the patients were advised by the chest Clinic specialist to use their nebulisers at home in 24 h, and how often patients used their nebuliser in reality (n=total number of answers. Percentage in brackets)</td>
<td>How often to use per day?</td>
</tr>
<tr>
<td>Advise by specialist of daily usage</td>
<td>2 (2.7%)</td>
</tr>
<tr>
<td>Daily usage by the patient</td>
<td>5 (6.7%)</td>
</tr>
</tbody>
</table>

(b) Data on how often changes were made in total (24 times), and if they were made, whose decision it was. Number of participants in the questionnaire: 75

<table>
<thead>
<tr>
<th>Changes made to advised frequency</th>
<th>Total</th>
<th>On advice of specialist</th>
<th>Own decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use it more often!</td>
<td>15 (50.0%)</td>
<td>9 (61.8%)</td>
<td>6 (31.6%)</td>
</tr>
<tr>
<td>Use it less often!</td>
<td>15 (50.0%)</td>
<td>2 (18.2%)</td>
<td>13 (68.4%)</td>
</tr>
</tbody>
</table>


DISCUSSION

Absolute indications for nebuliser treatment are only very few: drug formulation, e.g. rhDNase (not applicable in asthma and COPD patients), or patients too sick or disabled to use handheld inhalers (9). It is very often left to the clinician’s choice to commence patients on nebuliser treatment.

The British Thoracic Society as well as the ERS has strict guidelines for the use of domiciliary nebuliser treatment (15,17). In severe COPD, it recommends an assessment of every candidate by a respiratory physician. Eligible patients should undergo a short trial at home. Criteria, which promise benefit from home nebuliser treatment are: (a) an objective treatment response with an increase of more than 15% in the baseline peak flow rate or, if this is not the case, (b) the clinician’s judgement, when the patient experiences subjective benefits.

Only a limited number of COPD patients are likely to qualify for a nebuliser using the first criterion, which by definition labels almost all patients as asthmatic. On the other hand, as Muers discusses in detail (9), a measurable increase in peak flow does not necessarily correspond with psychological and subjective benefits. Small changes in a patient with severely impaired lung function can have a big impact on symptoms (18). This might be the case by other possible mechanisms besides bronchodilatation like an increased cardiac output or cerebral blood flow.

Impact on survival and mortality of domiciliary nebulisers vs inhalers could not be shown (13). The second criterion covers these possible mechanisms but none are easily measurable by the clinician and result in an entirely subjective decision being taken by the physician in many cases.

The frequency of side effects reported in our questionnaire is relatively low and (the most frequent being tremor and dry mouth) correlates well with other studies (12).

Serious side effects of especially beta-agonists, like symptoms of cardiac ischaemia or arrhythmias, were reported, but only in a few patients, although those could have dramatic consequences (19). Previous published results show that those side effects are mostly mild to moderate in nature, and deaths due to cardiac causes are very rare (12,15). A finding supporting this statement was that in random blood samples of acute admissions for exacerbation of asthma the systemic levels of beta-agonists were not different in people with or without domiciliary nebulisers (10).

Generally, side effects relate to the amount of drug used during the day, at least for beta-agonists (14,20).

The compliance to treatment in our patient group was good (around 75%). Interestingly changes to recommended dosing tended to decrease in frequency than to increase, which is reassuring regarding the safety issues.

Bosley et al. (11) showed recently (the adherence to treatment in their study was 44%) that the adherence to prescribed home nebuliser treatment highly depends on the quality of life, the patient experiences, depression and the feeling of being supported. This again emphasises the importance of a proper set-up of a nebuliser service, which should be run by specialist personnel. It also demonstrates that, if the target to provide a consistent better symptom relief and herewith quality of life is met, the compliance will automatically increase.

Generally, the results of this study strongly support the patient perception that nebulisers are helpful in the management of chronic lung disease, and especially COPD in the community. In particular, a high percentage of these patients felt that their nebulisers had made a big difference to their lives and that they would be lost without them. This result is in general agreement with the work of Muers (9), but contrasts with the medical establishment attitude that nebulisers have a limited role in long-term management of COPD (7,8,10). The reasons for this apparent anomaly are stated in the introduction. The cost of the treatment is certainly an issue, but if the patients’ perception that this treatment keeps them out of hospital and reduces calls on their GP is true, the cost-benefit changes. Certainly a previous study (10) contradicts this, showing no reduction in admission, and recently a national audit of COPD admissions in the U.K. identified multiple drug use and nebuliser treatment on
discharge as a predictor of readmission (21). Nevertheless, nebuliser use in this context may be a marker of severity, and this could confound results of studies examining different populations. It may be that the moderately severe patient may benefit with reduced admissions if given nebuliser treatment at home, whereas the severely ill COPD patient has gone beyond this aspect of treatment benefit. The study of Godden (22), where COPD admissions were avoided by providing hospital at home-type services certainly support this notion where nebuliser use and nursing support were the main interventions used to keep the less severely ill patient from admission. This study provides a perception, but is not conclusive. Further research should be targeted at this issue, and prospective randomised trials designed to address this question.

Symptom control is also reported as better and most, but not all patients felt that nebulisers were more effective than inhalers in helping their breathing. It is perhaps more surprising to understand, why patients, who answered negatively to this question continue to use a nebuliser, but it may be that the patients get other benefits as noted above that reinforce the use of their treatment. This is an important issue for doctors, who often dispense nebulisers on the basis of changes in lung function parameters or in some suggestion of reduced breathlessness or increased exercise ability. The results of this questionnaire suggest that the effect of nebuliser treatment may be much more complex, involving an interaction between physical, psychological and social gains.

The disadvantages of nebulisers are all too well recognised by patients in contrast to medical perception. A significant proportion of patients were concerned about the time taken for usage, the problems of over-reliance and dependence on treatment, and the difficulties that may arise in the case of equipment failure. The effect that this may have on compliance is also interesting with patients tending to reduce their use of nebulisers compared with the recommended frequency. In contrast, patients who have increased frequency of usage from the original prescription claim to have done so on the advice of a physician.

This study is limited by the number of respondents to the questionnaire, and the fact, that not all the patients suffered from COPD. Nevertheless, the response rate is fair and similar to other surveys. Even if the fine detail is obscured patient views about their treatment are important, and this study raises some interesting issues. The importance of involving patients and their perceptions of quality of life in treatment choices for cancer has recently been highlighted (23). This study suggests that a more patient-centred approach to nebuliser prescription may provide benefits to patients not measurable by traditional lung function testing and physician-estimated benefits to exercise capacity. More detailed enquiry as to the perceived patient benefits of nebuliser treatment using structured questionnaires may allow clinicians to make more rationale decisions in prescribing this treatment following a trial of nebuliser therapy.

REFERENCES

20. Walters EH, Cockcroft A, Griffiths T, Rocchioccioli K, Davies BH. Optimal dose of salbutamol respiratory solution: com-

