

## Adherence to Disease Management Interventions for COPD Patients: Patients' Perspectives

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### ABSTRACT

**Background:** The management of chronic obstructive pulmonary disease (COPD) requires a disease management approach—a combination of pharmacotherapy, pulmonary rehabilitation and behavioural changes. Patient adherence to therapy has been found to be poor, with a negative influence on outcomes.

**Aim:** To explore factors associated with adherence to disease management interventions from COPD patients' perspectives.

**Method:** A subset of 28 patients with moderate to severe COPD participating in a community-based randomised controlled trial were interviewed in depth about their health beliefs, attitudes to and experiences with their disease and its management, and their relationships with health professionals. The interviews were transcribed verbatim and analysed thematically.

**Results:** Patients with a range of sociodemographic backgrounds and varying disease severity were interviewed. Adherence to disease management programs in COPD was found to be a complex process driven by health beliefs and experiences related to patient, treatment, disease, and health professionals. 15 major themes related to adherent behaviour were identified. The balance between reservations in following treatment recommendations and motivating factors for following those recommendations was likely to determine decisions to adhere to disease management programs.

**Conclusion:** The study highlighted the importance of consultation with the patient in the management of COPD. Treatment recommendations that fitted into patients' existing routines were more likely to be successful. Health professionals could enhance adherence by being empathic, by improving patient knowledge about the disease and faith in the treatment, and by reducing their concerns about the treatment.

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### INTRODUCTION

Chronic obstructive pulmonary disease (COPD) is currently the fifth leading cause of global mortality.<sup>1</sup> By the year 2020, COPD is expected to become the world's third most common cause of death and the fifth leading cause of disease burden.<sup>2</sup> In Australia, people with COPD represent 1.6% of the population, with more than 20 000 new cases diagnosed every year.<sup>3</sup> COPD accounts for 4.8% of all deaths and is the fourth leading cause of death among males and the sixth among females.<sup>3</sup> Older people (above 65 years) account for two-thirds (66%) of those reporting COPD as their main disabling condition.<sup>3</sup> In 1999–2000, COPD was the principal diagnosis in 48 583 hospital separations accounting for 0.8% of all separations.<sup>3</sup>

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Smoking cessation is the single most effective and cost-effective way to reduce the risk of developing COPD and to arrest its progression.<sup>4</sup> A combination of treatments is often necessary to cope with the deteriorating respiratory function.<sup>4</sup> These include pharmacological (bronchodilators—beta<sub>2</sub> agonists, anticholinergics, methylxanthines, glucocorticosteroids, vaccines, antibiotics), non-pharmacological (pulmonary rehabilitation, oxygen, ventilatory support) and surgical (bullectomy, lung volume reduction surgery, lung transplantation). None of the existing drugs for COPD has been shown to modify the long-term decline in lung function. Team efforts of various health professionals and patients are essential for the success of COPD management programs. Assessment of patient commitment to the intended management is critical in both clinical practice and research.

Compliance is defined as 'the extent to which a person's behaviour (taking medications, following diets, executing lifestyle changes) coincides with medical or health advice'.<sup>5</sup> Although compliance used to be the common term in the literature, it is increasingly being replaced by the term 'adherence', which is less judgemental and more respectful of the role that patients can play in their own treatment.<sup>6</sup> Non-adherence has been found to contribute to morbidity and mortality and result in economic costs and waste of resources.<sup>7</sup> Long-term medication adherence for different diseases in various settings tends to converge to approximately 50%.<sup>8</sup>

It would be reasonable to assume that in a symptomatic disease such as COPD, patients would be highly adherent. However, poor adherence to drug therapy and disease management programs has been identified as the major factor resulting in the emergency hospitalisation of these patients, whilst a meta-analysis found the mean adherence to medical treatment was much less in pulmonary diseases (69%) compared to other chronic diseases.<sup>9-11</sup> Studies have shown non-adherence to be a multidimensional quandary in COPD and to include short-term and long-term medication non-adherence, non-adherence to lifestyle changes, non-participation in or early withdrawal from respiratory rehabilitation or exercise programs, failure to meet vaccination requirements, missing scheduled clinic or home visits, and inadequate monitoring of treatment response.<sup>10,12-26</sup> Adherence to lifestyle changes, such as diet, exercise, and smoking cessation are known to be the most difficult.<sup>27</sup> The three types of medication non-adherence—under-use, overuse and inappropriate use—have been reported among COPD patients.<sup>12,13,16-18,22,28,29</sup>

Prescription of complex medication regimens and multiple dosage forms is common in COPD, which could jeopardise their adherence.<sup>13</sup> Also, COPD patients often need to make alterations to their drug regimen depending on disease severity, respiratory tract infections and seasonal changes. It is not surprising in a disease like COPD, where patients are often encouraged to increase their doses when feeling unwell, that they may also decrease their doses when they feel well.<sup>12</sup> The same patient may demonstrate different adherence patterns on various occasions, based on disease severity, presence of comorbidities, complexity of drug regimen, types of drugs, and reinforcement and nature of follow-up from health professionals.<sup>17,30</sup>

Adherence is multifactorial and can be best understood within patients' physical, economic, psychological and social considerations. Very little attention has been paid to patients'

perspectives of illness and management. 'Why patients do or do not take their prescribed medications' is becoming the starting point for adherence research.<sup>31</sup> Social scientists use theories such as Health Belief Model, Locus of Control Theory, and Self-regulatory Model to explain health behaviours.<sup>32-34</sup> Qualitative methods are valuable for investigating patients' health decision-making processes and the reasons behind such decisions.<sup>35,36</sup> The potential of qualitative methods to contribute answers to questions not easily addressed by randomised controlled trials, thereby bridging the gap between scientific evidence and clinical practice, is well recognised.<sup>37</sup> This study aimed to explore factors associated with adherence to disease management interventions from COPD patients' perspectives, i.e. psychosocial factors influencing adherence to the various disease management programs: short-term and long-term medication adherence, smoking cessation, and ongoing participation in exercise programs.

#### METHOD

This study was nested within a prospective randomised controlled trial conducted through a major Melbourne teaching hospital. The controlled trial was designed to investigate the impact of a multidisciplinary community management program for patients with moderate to severe COPD (forced expiratory volume in 1 second < 60% predicted). The study evaluated the impact of an integrated community management program involving six-monthly patient home visits by a pharmacist and a nurse, and endpoints included patients' quality of life and hospital admission rates. The 173 subjects in the controlled trial were recruited from patients admitted to the hospital for an acute exacerbation of COPD in the preceding two years, a volunteer respiratory patients' database and respiratory disease support organisations.

During home visits, patients were invited to participate in in-depth interviews. A subset of participants was chosen based on their self-reported adherence, disease status, medications and management to give a suitable case mix, regardless of the arm of the controlled trial they belonged to.

Interviews of 30 to 100 minutes duration were conducted by a pharmacist in the patient's home during the clinical trial (July 2002 to April 2003). Spouses were included in the interviews at the patient's discretion. The interviewer explored the patient's health beliefs, experiences with and attitudes towards medications, disease conditions, management and health professionals, based on an interview guide developed for the study based on literature review. All the interviews were audiotaped and transcribed verbatim. All the transcripts were verified by the interviewer for their accuracy and analysed for relevant content and themes using the data management program NVivo.<sup>28</sup> Another pharmacist listened to all the tapes and verified the themes identified by the interviewer. The identified themes were discussed among all the authors. Data analysis and interviews occurred concurrently based on the theory of analytic induction.<sup>38</sup> The authors agreed that data pertaining to adherence reached saturation after 28 interviews. No new themes emerged in the last three interviews.

The controlled trial, including the in-depth interviews, had approval from The Alfred Human Research Ethics Committee and the Monash University Standing Committee on Ethics in Research Involving Humans. All the study participants provided written informed consent.

#### RESULTS

One hundred and seventy-three patients (mean age 70.0 ± 9.6 years) were enrolled in the trial; 108 (62%) were male. In-depth interviews were conducted with a subset of 28 patients chosen from the trial (Table 1). Two patients declined to be interviewed

due to health reasons. All those interviewed spoke fluent English. Two of the participants were married to each other and were living together. Five respondents had a documented diagnosis of heart failure, while three had ischaemic heart disease. Eight participants reported taking maintenance prednisolone.

**Table 1. Characteristics of participants (n = 28)**

Characteristic	n (%), mean ±SD
Gender (male)	21 (75%)
Age (years)	70.1 (±7.7)
Living arrangement	
Alone	13 (46%)
With spouse	13 (46%)
With family	2 (7.1%)
Highest education	
Primary	2 (7.1%)
Secondary (part or complete)	20 (71%)
Tertiary	6 (21%)
Smoking history	
Past smoker	21 (75%)
Current smoker	6 (21%)
Non smoker	1 (4%)
Pulmonary rehabilitation	16 (57%)
Home oxygen	7 (25%)
Compliance aid	18 (64%)
Complementary and alternative medicine	14 (50%)
Clinician managing respiratory condition	
General practitioner	13 (46%)
General practitioner+respiratory specialist	11 (39%)
Respiratory specialist	3 (11%)
General practitioner+cardiologist	1 (3.6%)
Forced expiratory volume in 1 second (FEV1)	1.03 (±0.47)
FEV1 (% predicted)	37.36 (±21.19)
Years of smoking	40.96 (±14.78)
Cigarettes per day	26.54 (±15.42)
Pack-years of smoking	56.43 (±35.22)
Prescribed medications	9.57 (±4.18)
COPD-related hospitalisations in last 2 years	1.57 (±2.12)

**Table 2. Themes identified from in-depth interviews**

Treatment	Patient	Disease	Health professional
Attitudes	Motivation/ determination	Acceptance/ denial	Faith
Faith			
Concerns			
Expectations			
Procrastination			
Desperation			
Embarrassment			
Knowledge	Emotions	Symptoms	Satisfaction
Medication regimen	Financial	Living with disease/ quality of life	Patient participation in decision making
Frequency			
Dosage forms			
Administration technique			
Sequence			
Tapering/alternating doses			
No. medications			
Physical properties			
Regimen changes			
Deviations		Prognosis	Empathy

Content and thematic analysis of the 28 interviews identified various themes related to patient beliefs and adherent behaviour. Fifteen major themes (Table 2) pertaining to treatment, disease, patient and health professionals emerged from the interviews.

### Attitudes to Treatment

#### Faith

Adherence to the recommended treatment was dictated by patients' faith in the treatment, which in turn was influenced by their own or others' prior experiences with the treatment. Health beliefs might undergo changes based on further experiences, especially one's own. Faith in health professionals and faith in treatment were interrelated. *'I found a while ago some tightness in my chest. Couldn't get breathing, [went] down to the doctor. He put me on the nebuliser for ten minutes and I found it good, and I started going on that first thing in the morning.'* (Patient 23) *'I went down with a chest infection a few times and I saw the doctor and he gave me one lot of antibiotics. "This should clear it up." Nothing happens so I go back again and he gives me the same thing again. Nothing happens and so I go back the third time and they give me something else and nothing happens. I said I'll get better myself.'* (Patient 19) *'Being told [to] is why I am taking [inhaled medications] all the time. Still not getting physical feedback from them. If that was all I was relying on, I wouldn't be taking them at all. I am not getting any. I am taking them because I was told to.'* (Patient 9)

#### Concerns

Concerns about side effects, dependence and tolerance were the major issues raised by patients for not wanting to use certain medications, especially long term. One's own experiences in the past or information gained through friends, health professionals or the media formed the basis for these concerns. Disease burden, prognosis, recognition of the importance of the treatment, unavailability of alternative modes of treatment and commonness of the untoward effects were found to influence patient concerns. Patients were prepared to put up with minor inconveniences due to the treatment if they were assured, or knew through previous experience that the treatment would improve their quality of life. *'I've seen a few people at [the respiratory support group] who are breaking their necks to get on oxygen because it's going to help them and I've seen them use it as a crutch and I don't want to do that ... I think it's like glasses; you put glasses on so that you can read properly and then you get so used to having them on that, you can't read without them.'* (Patient 22) *'[The respiratory specialist] said, "You shouldn't take prednisolone too much because it affects your immune system." and that bothers me.'* (Patient 8) *'I am damned if I do [take prednisolone] and I am damned if I don't. If I don't take it, I can't breathe and I'll die, which I have nearly done, and if I do take it I'll break another rib [due to osteoporosis].'* (Patient 28) *'I'm not going to live all that bloody long. What's the side effects going to do?'* (Patient 12)

Patients who believed in 'naturalness' considered medications as 'poisons' or 'harmful substances' and tried to avoid them as much as possible. *'The less medication you can take, the better; and, after all, medication is only man made ... and I'm a little bit on the natural side of life.'* (Patient 5)

#### Expectations

Patients had different expectations regarding the immediacy and extent of response from their treatment, which determined the way responses were evaluated. Lack of harm was 'satisfactory' for some patients, while some had high expectations that led to frustrations and disappointment. Patients who put their faith in

health professionals were found to continue using their medications regardless of the responses. *'I got very discouraged when I found [COPD medications] weren't working at all; I thought [they would be an] instant miracle.'* (Patient 26) *'You don't get any immediate [benefit], [medication] has got to get into your system; you can't expect to take something now and then it's going to work straight away. You've got to wait for a while. That's how I visualise things anyway.'* (Patient 27) *'[Chinese medicine] is certainly not doing any harm, and I think it does help a bit. I'm not saying it is the cure of all cures or anything like that, but it does help, that's for sure.'* (Patient 3) *'I don't feel any ... relief from the medications, I'm simply taking them because experts in their field told me that it's the thing that I should be doing, likewise the oxygen at night.'* (Patient 10)

#### Procrastination

Patients with COPD might put up with their symptoms and delay initiation of drug therapy and visits to the general practitioner. Concerns about the treatment, such as side effects, tolerance and dependence were the driving forces behind procrastination, which became less influential with disease progression. *'I don't take my [salbutamol] now because I use my relax breathing techniques that I've been taught and I try to get by on that and I just sit down and relax myself and get my breathing working. If I can do that, it usually subsides after five or ten minutes you know, so I try to avoid taking the [salbutamol].'* (Patient 21) *'Last time when I really got crook, I used to fight it, like trying to beat it; but this time I'm not. It's more or less I know now I'm going to be on [the nebuliser] until I kick the bucket. So I've got to get used to it ... So I don't fight it any more.'* (Patient 1)

#### Desperation

Concerns about the future, disease burden and consequent poor quality of life were found to favourably influence medication use. Balance between these concerns and previously discussed factors such as concerns about the treatment, lack of response from treatment and inconveniences due to treatment determined the intensity of desperation. *'Well, I'm willing to have a go at [prednisolone]; I don't care if I blow up again. I couldn't get my slippers on last time, but if I could take four every day, I would take four every day, if that would help me, or two if that would help. As long as it clears me you know, helps my breathing, I don't want to sit here on this [nebuliser] any more all the time.'* (Patient 1)

#### Embarrassment

Patients reported being embarrassed to use their inhaled medications and oxygen in public, necessitating adaptations to those situations. Embarrassment and not being a 'group person' were reasons given for not attending pulmonary rehabilitation or exercise programs. Patient attitudes might undergo changes with the progression of the disease or after knowing the experiences of other patients. *'I am a person who keeps to myself. In fact, I detest having company when I am doing something. I prefer to do [exercises] on my own ... I'm not a group person. I get very embarrassed.'* (Patient 26) *'That's what made him put off getting [oxygen] in the first place because of people seeing that he was on it ... and then the people he spoke to up at [the respiratory support group] said the same thing. One of the chaps said ... about going shopping [with the oxygen] the first time that everyone would look at him and he said that they never took any notice of him. So then we decided he would give it a go.'* (Spouse of patient 8)

### Knowledge about the Treatment

Understanding of the disease process and recognising the role of treatment made patients more realistic about the treatment outcomes, which in turn promoted adherence. *'The emphysema is ongoing; I think the medication is keeping it at bay. That's what I think. I think I'll need them, unless something comes up in the future.'* (Patient 16)

Knowledge about medications, especially their adverse effects, made patients wary of using such medications. *'I certainly don't want to start on [bupropion] when I've heard so many stories about, you know, bad reactions.'* (Patient 26)

### Medication Regimen-Related Factors

#### Frequency of Dosage

Patients who had strict routines or who could fit medication-taking into their daily routines found even complex regimens easy to cope with. Factors distracting routines such as holidays or emergencies were found to jeopardise adherence, unless special precautions were taken. *'I had over twelve years in the navy, so I think I might have learnt something out of it. You know, you get a lot of discipline and strict routines, that was it.'* (Patient 2) *'I was so involved with the funeral [of my father] and the family that I just didn't have any perception of where I was going, I really didn't... I overlooked everything... If I had been at home it would have been a different situation, but it was one of those situations where it got the better of me.'* (Patient 11) *'Sometimes I'd miss a meal in the middle of the day whereas morning and evening meals, definitely every day. So two times is easier than three, and four—there are no meals that coinciding with it, so that would be difficult.'* (Patient 11)

Symptoms prompted medication taking in patients with more severe disease. Morning doses seemed to be the easiest to remember due to minimal distractions. *'I take one every four hours. When it gets close to the four-hour dose, I'm starting to struggle. So it's a sort of a reminder that I'm due. Rather than just a cough, my body is telling me that I need something.'* (Patient 8) *'I kept forgetting the [fluticasone+salmeterol] because it was at bed time. I'd be in bed and couldn't be bothered getting up again to take it.'* (Patient 17)

#### Nature of Dosage Forms

Physically challenging and inconvenient dosage forms had deleterious effects on patients' adherence with such dosage forms. Patients' perceptions about the complexity of the various dosage forms were found to determine their satisfaction with the dosage forms. *'The oxygen is the most inconvenient... You've got to drag it around with you... even when you are walking around. I reckon the energy required to pull it around just about outweighs the fix of oxygen!'* (Patient 7) *'When I'm really ill and I have to go and set up the pump, that can be a hassle in itself; just setting it all up and getting things going you know; but the [spacer], it's not quite as simple as just taking it direct with a puffer, but it's pretty handy you know, just shake your stuff up, put it in and take a couple of puffs.'* (Patient 2) *'If you are in trouble, the [spacer] would be the one if you are home, but when I'm out I find instead of carrying that big one, I just carry that little portable [spacer].'* (Patient 5)

Patients' perception of the efficacy of the various dosage forms might influence their acute and chronic medication use. *'When you do the Accuhaler, you are not too sure whether you've got it. You're not too sure whether you're going to get a dose or not, 'cause it's all bloody concealed. But when you've got the [metered dose inhaler], you can hear it.'* (Patient 12)

#### Administration Technique

Patients received minimal instructions regarding administration techniques for inhaled medications from their health professionals. Some informants believed that the competency of administration techniques was stable over time, though some admitted 'becoming a little slack' over time. *'No, I've never had any advice on how to use them. Read the directions when you buy them. Whether I'm doing it right, I don't know; but I feel okay, so I must be doing something right.'* (Patient 17) *'Once you learn to walk, you walk the same way all the time. You learn to puff [inhaler], you puff that the same way all the time.'* (Patient 23)

#### Sequence of Administration

Initiation of multiple inhaled medications created confusion in patients, especially regarding their sequence, if not supported by adequate instructions. *'I was having [my inhalers] in the wrong way, because I didn't know. Even in hospital I was on all these [inhalers] and they just gave me whole lot at once. There was no certain way of taking them.'* (Patient 16)

#### Tapering or Alternating Doses

Patients had to devise their own techniques to cope with challenges in managing tapering or alternating doses. According to a patient who was prescribed varying strengths of thyroxine: *'The [thyroxine bottle] with the label facing me, the prescription label, the chemist label facing me is the one I take today and then when I have taken it, I turn that bottle around and turn the other one around; and tomorrow I take the one with the label facing me, prescription label facing me. So that's the way I work it out.'* (Patient 20)

#### Number of Medications

The number of medications was not found to cause many adherence problems, in so far as they fitted into patients' routines. *'Look, it's no bother once you start, put them into a routine; then it's not really a bother to take them.'* (Patient 11)

#### Physical Properties

Poor physical properties of medications, such as odour, taste and size made such products less appealing and subsequently raised adherence challenges. *'I felt that the powder [in fluticasone Accuhaler] clung to my throat and I didn't feel as comfortable as I do with [budesonide]. The doctor had no difficulty with that, he just put me back on [budesonide].'* (Patient 5) *'I don't like the taste of [ipratropium]. It tastes foul... acidy sort of. It's not very nice. [Salbutamol] is much smoother and easier to take.'* (Patient 26)

#### Changes in Existing Regimen

Changes in regimens that were outside existing routines had the risk of being rejected. *'A few weeks ago now, I went to my specialist... and he said "There is some noise at the back of your lungs. I think you better get your nebuliser out and, of course, you use it four times a day." So I'm using it four times a day, but sometimes you can't use it four times a day. If you've got to go out, well maybe three times a day. Sometimes you're working and you forget. So sometimes it is twice a day, but if I felt the need for it in between, I would use it.'* (Patient 20)

### Deviations from Recommended Treatment

Patients made both intentional and unintentional deviations from their recommended management. Overuse was found to be driven by disease symptoms while under-use was driven by concerns about the treatment or due to difficulties in fitting the

regimen into ongoing routines. Intentional deviations were often guided by previous experiences. *'I've got [the oxygen flow rate] on three but [the respiratory specialist] says two, but I put it higher on three because I find two is not, I can't handle two, I've got to have it on the three. He ... doesn't say anything, he just lets it go.'* (Patient 3) *'If you keep overdosing yourself, you're going to build up resistance to the bloody lollies, the pills, right? So if you take the minimum dose all the time, you are going to build up resistance to it but not as quick as if you overdose. Pretty simple.'* (Patient 12)

Patients who fully relied on their health professionals in making health decisions did not make any intentional deviations. *'I never alter my medication without the doctors, I wouldn't be game to. I don't think I know enough about the medication.'* (Patient 22)

Unintentional deviations were less in symptomatic patients, patients with strict routines for taking their medicines and in those who had some kind of reminder systems, such as storing their medications close to the place where they needed to use them. *'I don't have to remind him [to use respiratory medications] because most times he does something and then he can't do any more, so he dives for his medication.'* (Spouse of patient 6) *'In the morning, I have [the medications]. Get up, put the kettle on, by the time the kettle takes to boil, it's time to take the pills ... habit—just knowing when I'm making a cup of tea, so it's just habit.'* (Patient 13)

Some of the most common reasons for unintentional deviations from the recommended treatment were forgetting due to disruptions to routines (e.g. television, alcohol, guests) especially in the absence of reminder systems, getting confused with the recommendations and running out of medications. *'Watching television, getting involved in the newspaper or something like that and all of a sudden you realise that it's bedtime and go to bed and forget to take it.'* (Patient 23)

Unintentional deviations due to forgetting or other limiting circumstances could mark the beginning of experimentation with drug therapies. Worsening of symptoms or disease status following experimentation might persuade restarting of therapy, while lack of any noticeable differences after stopping might result in intentional deviations including permanent discontinuation of such therapies. *'I kept forgetting to take [fluticasone+salmeterol] at night and it didn't seem to do me any harm; so that's why I mentioned it to [the specialist]. You know, often I would forget it and I'm in bed and I can't be bothered getting up again. But I don't really think I need it. He said 'If you don't feel you need it, give it a try without it.' and that's what I've been doing.'* (Patient 17) *'I was away for a weekend, then I didn't have [salbutamol] and I felt quite distressed; I convinced myself that I definitely needed it so much we came back ... to pick up the inhaler.'* (Patient 9)

#### **Motivation/Determination**

Friends and family, response to treatment, disease burden, prognosis and knowledge about the disease were some common motivating factors for better adherence. *'I'll be honest with you, I'm lazy. If I don't want to do something I won't do it and I've got no reason to do anything, all I'm going to do is to sit and pass the time. That's what all the blokes are doing, pass the time.'* (Patient 12) *'When you've been smoking for hell of a long time, for years, it's hard to give them up; but if you want to stay alive ... I've been given four years if I don't get off them. I want to be here a bit more than four years. Christ! I'll only be 66 or something. I've got thirteen grand kids, got four lovely kids of my own. I've got good friends and I enjoy life; so I've just got to get off the bloody things. Even if it only gives me another four years, that's eight years I've got.'* (Patient 1)

#### **Emotions**

Emotional incidents, especially deaths of dear ones, posed threats to patient adherence. In the absence of strong motivating factors, such non-adherent behaviours were likely to persist. *'My wife died in '96. I think that was when I started not to look after myself and maybe over indulged in the "pleasures" of life and I can remember just getting run down and tired and too much drinking and too much smoking, too much of a lot of things.'* (Patient 15)

#### **Financial Issues**

Cost of treatment was largely not an issue in following recommended treatment. The exceptions were lack of availability of oxygen for patients who did not meet the recommended criteria, purchase of items not funded through the Pharmaceutical Benefits Scheme (PBS), specialist visits and private hospital care. Some patients had given up smoking merely due to financial concerns, while the affordability of smoking cessation therapies encouraged some patients to try them. *'[Bupropion] had come on to the PBS. It was only going to cost me \$3.60. Even if it hadn't been on the [PBS], if you weren't a pensioner, it was only \$22. I mean it was well worth trying. So I thought well, what have I got to lose?'* (Patient 17) *'I am just waiting for the next episode or the next attack of breathlessness or pneumonia or whatever it is that causes me to go into hospital and then I will get tested again and if I meet the criteria I will get oxygen. I can buy oxygen, but I can't afford it. I can buy it at so much a month, but being on the pension, you can't afford it.'* (Patient 6) *'I still kept smoking until last year and I never gave it away because of my health. It was the cost, I couldn't afford it.'* (Patient 19)

#### **Acceptance/Denial of Illness**

Patients put up with their symptoms and stayed in denial until impacted by critical incidents such as hospitalisation or an acute incident of shortness of breath. *'I have been one who hasn't been one who goes to the doctor. I try and avoid it. I stay in denial; it's not bad, it will get better.'* (Patient 15) *'The reason I gave up smoking was, I was at a friend's place in the evening, autumn, winter out in the country where I'd been smoking like mad all night. Went outside for a breath of air and my air supply went; I thought I was going to die. They rushed me inside and put me to bed. A short time later I got up and was walking around and I drove home, but it frightened hell out of me, because I thought I was looking at my future, 'the man with no air'. I gave up smoking like that.'* (Patient 9)

#### **Symptomatology**

Symptoms of COPD acted as prompts for medication taking, whereas lack of symptoms resulted in non-adherent behaviours. Symptoms were found to be influenced by external factors (e.g. weather). *'If I'm breathless, I'll take [salbutamol]. Somebody told me you should take it before you start exercising; I keep forgetting ... because I feel good.'* (Patient 16)

#### **Living with the Disease/Quality of Life**

Attitudes towards medications and management were influenced by disease-related quality of life. *'[The respiratory condition] is more immediately life threatening than my cholesterol is ... and certainly it's much more restrictive on my quality of life than having a 6.8 [mmol/L] cholesterol.'* (Patient 10) *'I did go to [the hospital] for about a few times and they did teach me different exercises two or three years ago. I don't, I can't put them into action because the older I'm getting, I just, I can't do it. Makes my breathing, exercises—they take too much out of me.'* (Patient 4)

Instability of COPD and associated poor quality of life resulted in frustration. Patients who had sufficient knowledge about the disease and who accepted their disease were coping well. 'Sometimes I get cross with myself because I can't do what I used to do but I can do most things. I can't do house work, I can't bend.' (Patient 5) 'I don't think you can get rid of [COPD], I don't think. You've just got to put up with it, like take your medication.' (Patient 27)

#### Prognosis

Knowledge about the poor prognosis of COPD convinced some patients to opt for quality of life rather than quantity. On the other hand, patients who understood the role of management were realistic about the outcomes, which helped in avoiding frustrations about the condition and disappointment with the treatment. 'I enjoy smoking, I like to smoke, I like the taste, end of story ... No matter what they do, they're not going to cure me, so you might as well enjoy it.' (Patient 12) 'I don't expect [COPD] to get much better, I don't expect that at all ... As far as I know, giving up smoking your lungs get better. They wouldn't be 100%, but they recover a certain amount. I've been off smoking now for about six years completely.' (Patient 23)

#### Faith in Health Professionals

Some patients were of the opinion that COPD needed a respiratory specialist to manage it; others believed that the treatment offered by a specialist would be no different to their general practitioner. However, advice from specialists was highly regarded. Health professionals could allay concerns about treatment and in turn promote adherence. 'I'd pay more heed, for a particular condition such as my respiratory condition, to a respiratory physician than a GP.' (Patient 10) 'I think when it comes to respiratory specialists, I would be surprised if they could do any different to what my GP is doing at the moment; I'm not convinced that they would. I've talked to others who have got respiratory conditions and I don't believe that they are on anything spectacularly different to the GP's treatment.' (Patient 11) 'I know that if [the GP] explained [about bupropion] to me properly and convinced me, that would be good enough for me. Now if he didn't convince me, I don't know what I would do there. If he couldn't convince me, I probably wouldn't take it.' (Patient 15)

#### Satisfaction with Health Professionals

Satisfaction with health professionals was determined by the amount of time they spend with patients, the nature of their interaction with patients and the quantity of information shared with patients, than the efficacy of the treatment. COPD patients expected their health professionals to spend adequate time with them and explain their disease status and its prognosis. Failure to meet these expectations resulted in dissatisfaction. 'The doctor [specialist], he was alright, but he showed me the X-rays and things like that, which I thought was good. He calls a spade a spade you know, which I like. That's what I like, one who tells the truth.' (Patient 16) 'My GP is very good but the respiratory man when I went to see him, I used to go and see him, he never used to check my chest out. He never listened to my chest, which annoyed me.' (Patient 20) '[The traditional Chinese medicine practitioner] will go through and explain all that and do all these sorts of things, which the local GP and even the specialist don't.' (Patient 3)

#### Patient Participation in Decision-Making

Shared decision-making and adequate patient involvement in management were found to have better outcomes. '[The doctor] sort of leaves it to me. He tells me ... what the ideal thing is

and that you can weigh it up then to what you think.' (Patient 7) 'I've usually got some [amoxicillin+potassium clavulanate] in the back of the cupboard there and if I can't get to the doctor fast, I'll start taking that.' (Patient 11)

#### Empathy

Participants expected their health professionals to be empathic and understanding regardless of their health behaviours. However, unfriendly approaches such as 'bullying' and 'sneering' helped to achieve smoking cessation in some patients—an individual might respond differently to similar approaches. 'The specialist don't want to know you if you are a smoker.' (Patient 28) 'The GP ... charged me \$76 for a consultation and in brackets he put the cost of a carton of cigarettes. That only made me angry; I didn't want to accept it.' (Patient 14) '[The consultant] said she wasn't going to waste her time treating me and I was far too intelligent to still be smoking ... she said "You're just going to die unless you stop smoking." and I never ever had another one.' (Patient 14)

#### DISCUSSION

The interviews helped in gaining an understanding of the factors influencing adherence to COPD management programs from the patients' perspectives, which would not have been possible by using other methods for assessing adherence. Factors relating to the patient, treatment, disease and health professionals were found to influence adherence. As reported in the literature, multiple comorbidities were common among the patients, underlining the relevance of the findings of the current study in other patient populations, particularly those with other chronic diseases.<sup>24,39</sup>

Faith in the treatment was a critical determinant of adherence to the recommended treatment among the participants. Experience and satisfaction with the treatment were found to influence one's faith in the treatment. The Health Belief Model suggests that a patient's perception of the effectiveness of a recommended behaviour (action) predicts the likelihood of taking up that behaviour.<sup>32</sup> Patients' perceived benefits from the treatment is known to be associated with medication use from studies on various patient groups.<sup>22,36,40-42</sup>

Concerns about treatment, such as side effects, tolerance, and dependence, favoured procrastination in initiating drug therapy; procrastination became less likely with disease progression. Medication-related concerns, especially side effects, have been raised in previous studies on various patient groups.<sup>36,42-45</sup> Concerns about 'addiction' to steroid medication and oxygen in the present study have been reported in previous studies of patients with chronic respiratory diseases.<sup>40,46,47</sup>

Participants experimented with their recommended treatment, either explicitly or subconsciously, to establish its value. Experiences from experimentation influenced future decisions regarding those treatments. Experimentation with medications has been reported previously among chronically ill patients including those with COPD.<sup>40,48,49</sup>

Embarrassment in using inhaler devices and oxygen in public was reported by many participants. However, such concerns lessened with disease progression, with participation in educational programs or with experience in using the medication. In previous studies, embarrassment in using long-term oxygen was an impediment to its use, while in contrast, feeling ashamed about having asthma facilitated adherence to prophylactic asthma medication in adolescents.<sup>40,50</sup>

Participants wanted to know more about their disease and its management. Many had completed at least one course of pulmonary rehabilitation and some were members of respiratory support groups. Such patients had a good understanding of the disease, the role of treatment and its effects. However, knowledge about inhaled steroids has been shown to have

mixed impact on adherence among patients with chronic respiratory ailments.<sup>22,51</sup> A lack of association between perceived knowledge and self-management knowledge scores was observed among COPD patients in a study that explored the influence of psychological characteristics in COPD self-management.<sup>52</sup> This finding has major implications for COPD education programs. Patients who assume that they know enough are unlikely to be motivated for further education. For optimal use of health resources, it is critical that patient knowledge and attitudes are screened prior to recruiting them for disease management programs involving education so that individual needs may be addressed.

Cost of treatment is generally regarded as a barrier to adherence.<sup>53</sup> With the exceptions of non-PBS and non-prescription items in a few patients, cost of treatment had no major influence on non-adherence among the participants. In Australia, health care is affordable due to government subsidised prescription medicines (the PBS), especially for the elderly.

The lack of association between regimen complexity and adherence observed among the participants is in accordance with the literature.<sup>12,21</sup> However, findings from the present study contradict the popular belief that adherence decreases with the length of medical treatment and over time.<sup>53,54</sup> According to a study of long-term oxygen users, patients who were unable or unwilling to incorporate oxygen use into an activity (e.g. going out) gave up that activity.<sup>40</sup> 'Treatment accommodation' is the extent to which a standardised treatment approach can accommodate to the complex and unique demands of patients' lives.<sup>55</sup> Our study findings suggest that once a treatment had been accepted by the patient it became part of their life, built into the daily routine (treatment accommodation) and adherence was no longer an issue. 'Routinising', the ability to fit a medication regimen to one's daily routine has been recognised as a major determinant of improved adherence.<sup>56</sup>

Risk factors for either intentional or unintentional non-adherence to medications mentioned by the participants were similar to the findings in previous studies of patients with chronic respiratory ailments.<sup>13,17-19,36,40,51,57</sup> Poor prognosis of COPD was the reason given by some patients for their non-adherent behaviour, such as failure to give up smoking. Based on observations during a qualitative study of Swedish patients with chronic heart failure, Stromberg et al. suggested that patients give such excuses to get away with non-adherent behaviour.<sup>45</sup>

Stable family life and living with a spouse are known to be associated with better adherence.<sup>15,19</sup> In the present study, family and friends were found to motivate patients towards better adherence. The greater adherence by patients living with their partners might be due to greater stability of married life or active assistance from the spouse in maintaining adherence or the general social support received when living with a spouse. Persons with problem drinking, compared with those without problem drinking, were more likely to miss a dose because they forgot or because they ran out of their medicine.

Changes in adherence patterns with disease severity and symptoms observed in the present study have been reported in previous studies among patients with COPD.<sup>15,17,21,22,58</sup> However, it is unlikely that health behaviours are determined by 'perceived seriousness (severity) of disease' or 'symptom perception' alone. Lack of significant difference in medication adherence in a group of COPD patients with varying severities and demonstration of very poor adherence even by COPD patients who had hospitalisations, emergency department admissions, night awakenings and high prednisolone requirement, suggest that patients' health decisions are likely to result from an interaction of various other factors.<sup>20,51</sup>

A patient's faith in the prescriber, satisfaction with health professionals, and good communication between patients and health professionals are critical for optimal adherence.<sup>15,18,43,59,60</sup> COPD patients' satisfaction with their health professionals was based on the amount of time and the quantity of health information shared by their health professional. Many patients heeded advice from respiratory specialists more than that from their general practitioners, which may be due to their longer availability for consultation or perception of their greater training in managing them. Similar to the findings in a study of HIV patients, some participants, especially those who continued to smoke, felt that their physicians treated them inhumanely and did not have their best interests in mind.<sup>42</sup> Empathy in practitioner relationships is postulated as necessary for adherence to therapeutic regimens. According to Vermeire et al., 'the backbone of the concordance model is the patient as a decision maker and a cornerstone is professional empathy'.<sup>61</sup> Better communication between health professionals and COPD patients might improve patient satisfaction about treatment and might in turn improve adherence.

Many participants had autonomy with their management (especially acute symptoms) while others were passive in their approach. Nevertheless, control over management is unlikely to be a significant independent predictor of treatment non-adherence. The failure of the Locus of Control Theory in explaining any significant proportion of variance in adherence in previous studies in patients with chronic ailments supports this argument.<sup>33,62,63</sup> Critical incidents and progression of the disease forced many of the participants to attend to their disease. Similar to the findings in a study on primary care patients, many COPD patients continued to fight the disease and tended to use the least amount of medication possible.<sup>48</sup> Patients' understanding and acceptance of the disease, and correct knowledge about the role of management, are critical for the success of COPD programs.

According to Leventhal's Self-regulatory Model, beliefs and behaviours interact in a dynamic way.<sup>34</sup> An act of balancing was observed among participants where they weighed the advantages and disadvantages in following the recommendations. The experimentation reported by some participants further confirms the dynamic nature of adherence in the COPD population. The greater perceived benefits over concerns might account for the high self-reported adherence among informants, regardless of the barriers to adherence identified through the interviews.

Our findings should be interpreted with caution. Patients participating in clinical trials and members of patient support groups tend to be more motivated and therefore their health beliefs could be different from those of the general patient population. However, all of the interviewees admitted exhibiting non-adherent behaviours at some stage in their lives. All except one patient had a history of smoking, which in itself is a demonstration of non-adherent behaviour (in terms of today's accepted social norms). The cross-sectional study design did not allow assessment of change in adherence patterns over time. As all the participants were Caucasians and spoke English, our findings might not be transferable across all COPD populations, especially in those with different sociocultural backgrounds.

In conclusion, adherence to COPD disease management programs was found to be driven by patient health beliefs and their experiences of treatment, disease, and health professionals. The balance between reservations in following the treatment recommendations and motivating factors for following them is likely to determine patients' adherence decisions. Taking patient preferences into account when treatment decisions are made is critical for optimal adherence. Treatment recommendations that fit into existing routines are more likely to be successful. Health professionals might be able to enhance patient adherence by being empathic, by improving patients' disease knowledge and faith in the treatment, and by reducing their concerns about the treatment.

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