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#### **ORIGINAL RESEARCH**

# The impact of prescription charges on asthma patients is uneven and unpredictable: evidence from qualitative interviews

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#### **Abstract**

Aim: To explore whether, and how, prescription charges affect asthma patients' disease management behaviour.

Method: Thirty qualitative interviews.

Results: Interviewees were aged between 21 and 59, 21 were women, 24 were paying individual prescription charges, and six had prepayment certificates (PPCs). Most had a  $\beta_2$ -agonist 'reliever' and a steroid 'preventer' inhaler. Prescription charges posed affordability issues for some, and for two patients cost-related reduction in 'preventer' use affected asthma control negatively. Many described various ways of keeping medication cost down. Affordability issues, negative views on paying charges, and whether interviewees viewed their asthma medication as essential, were influential factors. Steroid inhalers were viewed more commonly as being less essential and affected by cost. The episodic nature of asthma meant that predicting benefit from PPCs was difficult.

**Conclusion:** This study strengthens existing evidence that medication cost is a factor in asthma patients' management decisions, with a potential cost-related impact on asthma control.

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#### Introduction

Asthma is a worldwide problem, with increasing prevalence and significant effects on morbidity and mortality. In the UK there are 5.2 million people with asthma, resulting in at least 12.7 million lost work days, leading to an estimated bill for lost productivity of £1.2 billion. There are over 4.1 million consultations with general practitioners (GPs) each year, 69,000 hospital admissions for asthma, and over 1,400 deaths.

Well established and up-to-date clinical treatment guidelines exist in the UK<sup>3</sup> and other countries, including the United States.<sup>4</sup> However, the success of appropriately prescribed treatment depends on patients adhering to recommendations and treatment. Nevertheless, adherence to

asthma medication is poor,<sup>5,6</sup> causing increased disease severity and unnecessary hospital admissions<sup>7,8</sup> as well as death.<sup>9</sup> In the UK, it is estimated that non-adherence to asthma medication contributes to between 18% and 48% of asthma deaths.<sup>5</sup>

It is known that a multitude of factors impact on patients' management decisions and medicines adherence.<sup>10</sup> These include fear of adverse effects, a belief that the medication is of no benefit or is not necessary, a sense that asthma is not a chronic condition when one is symptom free (so medication is only needed intermittently), and the inconvenience of medication use or stigma.<sup>10,11</sup> Another factor is the cost of obtaining medication, and international evidence shows that this impacts negatively on the use of medicines in general<sup>12,13</sup> as well as on asthma medicines in particular.<sup>14-16</sup>

The impact of medication cost on adherence has received

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relatively little research attention in England, which may be explained by the relatively high level of prescription charge exemption. Overall, as many as 88.6% of prescription items are dispensed free of charge, 59.7% of which are for people aged 60 and over, who are charge exempt.<sup>17</sup> Further exemptions are granted to those aged under 16 years of age, those on low income, and those with various medical conditions such as diabetes.<sup>18</sup> This leaves about 50% of the adult population liable to prescription charges.<sup>17,19</sup> Asthma is not one of the medical conditions which qualifies for exemption.<sup>18</sup>

If prescription charges apply, their current cost in England is a relatively high flat fee of £7.10 (£6.30/6.40 at the time of the study) for each prescribed item. As asthma is a chronic inflammatory disorder resulting in reversible constriction of the airways, treatment consists of symptom management – usually through the use of an inhaled  $\beta_2$ -agonist – and prevention of attacks – where inhaled corticosteroids (ICS) are the mainstay of treatment. During episodes of asthma exacerbations patients may require additional medication such as antibiotics and/or oral corticosteroids, each incurring an individual prescription charge.

The sparse UK research evidence has shown that the cost of medication does influence non-exempt patients' management decisions, particularly if they are on lower incomes.<sup>20</sup> Bronchodilator and particularly steroid inhalers are among those commonly not dispensed on cost grounds.<sup>21</sup> However, despite the existence of some qualitative focus group evidence on the issue in general,<sup>22</sup> there is no detailed information on the impact of medication cost on individual asthma patients. The aim of this study therefore was to explore whether, and how, the cost of prescription charges affects asthma patients' disease management behaviour.

#### Method

The study employed qualitative interviews and, since cost only plays a role for those paying charges, <sup>22</sup> non-exempt asthmatics were targeted. Following local research and university ethics committee approval, three general practice surgeries in the Northwest of England mailed 602 asthma patients, aged 18 to 59, thus including those potentially liable to prescription charges – information not held on GP computer systems.

Fifty-two patients responded, 12 of whom were exempt. Thirty non-exempt respondents were interviewed in their own home or place of work during February to May 2004. Following informed written consent, semi-structured interviews were conducted using a topic guide based on the existing literature and the author's previous research (see Appendix 1 at www.thepcrj.org).<sup>20-22</sup> Interviews lasted between 15 and 65 minutes (mean 37 mins), and were tape-

recorded and transcribed verbatim. Transcripts were read repeatedly, common themes identified, and a thematic framework developed, which was informed by the topic guide. The thematic framework was then applied to the transcripts, and its key themes, with sub-categories, used to form charts. Distilled summaries of issues, with reference to the location in the original transcript, were used to populate the charts. This approach to data analysis was adopted since it allows an overview of the data where associations (and contradictions) can be explored for further explanation and interpretation.<sup>23,24</sup> The above process was led by the author but was reviewed with her colleague and mentor at various stages, to ensure validity of data analysis and discussion of interpretation and meaning.

#### Results

#### Background information on asthma interviewees

Twenty-one of the interviewees (70%) were women. Mean age was 44 years (range 21 to 59). Interviewees paid prescription charges currently (n=23), until recently (n=1), or had PPCs (n=6). They were working (n=25) or their partner was (n=4), and they had a wide range of incomes. Table 1 shows further detail.

All interviewees had a  $\beta_2$ -agonist ('reliever') inhaler, salbutamol for most (n=26). The majority (n=25) had an ICS ('preventer') inhaler, and seven had an additional regular long-acting  $\beta_2$ -agonist (LABA). The majority of regular repeat prescriptions were issued on a monthly basis. Further detail can be found in Tables 2 and 3.

#### Medication cost, affordability and asthma control

As interviewees were aware of the study purpose, half raised the issue of medication cost without prompting. Even though the prescription charge did not seem to stop most interviewees obtaining their asthma medication, it had a significant effect on two, who reduced the use of their ICS inhalers purely on the grounds of cost and affordability – which, for both, meant that their asthma control was affected negatively. One of the two was a 21-year old nursing student who was on a small monthly bursary of £406:

"I'm meant to be on salbutamol .. as a reliever, and the Becotide® as a preventer, but because [of].. prescription charges [...] If you're getting the two you have to pay for double, don't you. So I don't use the brown one at all now." (ID23)

As she had been asthmatic since childhood, and had been using both types of inhalers at a time when she still qualified for age-related exemption, she compared her inhaler use then and now. She used a 'preventer' then, was aware of its benefits, yet did not use it now because of its cost. It became clear that this interviewee was using her 'reliever' several times a day every day, suggesting poor asthma control.

£40,000 +

[missina]

Table 1. Demographics of interviewees (total n 30).			
N (%)	Asthma		
Gender: male	9		
Age			
20 – 29	3		
30 – 44	14		
45 – 60	13		
Rx charge			
Pays	23		
PPC	6		
Exempt	1		
Working status			
Full-time	16		
Part-time	9		
Spouse/partner works	4		
Full-time student	1		
Household income			
< 10,000	3		
£10,000 - 24,999	4		
£25,000 - £39,999	6		

NB. Poverty is specified as 60% of median income – adjusted for number in household (http://www.jrf.org.uk/knowledge/findings/socialpolicy/043.asp) In 2003/04, the median personal income was £11,800; median household income was £21,700; the higher rate of tax was paid on incomes over £35,115 (http://www.guardian.co.uk/business/2003/sep/29/politics.economicpolicy)

[12]

Another lady in her mid-fifties described how her financial situation in the last few years had been such that it made her reduce her inhaler use, which had led to worse asthma control:

"I must admit the last three years ... I've not .. been for the inhalers as much as I used to, mainly because of [..] my financial position, and I'm not just saying that because you're here, [...], it was a hard decision sometimes. [...] With not using it [Ventolin® and Becotide®] as often as you should, [..] you can tell, ooh, [...] the only way I can describe it, it's like a weight on your chest." (ID17)

The cost of prescription charges did not seem to impact on the remaining interviewees in a way that had a marked negative effect on asthma control, and several interviewees said they could afford the required prescription charges.

Nevertheless, the majority of interviewees, whether more or less affluent, had views on prescription charges. Many commented that their cost was too high, which was particularly important when more than one item was prescribed, thus incurring several prescription charges. Many disagreed with having to pay for asthma medication, which they felt should qualify for charge exemption or subsidy. It seemed that it was not merely cost and affordability that impacted on interviewees' management of their asthma, but

Table 2. Prescribed asthma medication.			
	n		
Adrenoceptor (mainly $\beta_2$ ) agonist inhaler ('reliever')			
Salbutamol (Ventolin® / Salamol®)	26		
Terbutalin (Bricanyl®)	1		
Ipratropium + salbutamol (Combivent®)	2		
Not known which 'reliever'	1		
Regular bronchodilator inhaler (not for immediate relief)			
No regular bronchodilator used	23		
Salmeterol (Serevent®)	5		
Formoterol	1		
Salmeterol + fluticasone (Seretide®)	1		
Steroid inhaler ('preventer')			
No steroid inhaler used	5		
Beclometasone (Becotide® / Becloforte® / Qvar®)	11		
Fluticasone (Flixotide®)	4		
Budesonide (Pulmicort®)	2		
Budesonide + Formoterol (Symbicort®)	2		
Not known which 'preventer'	6		

Table 3. Frequency of repeat prescription (Rx) and number of items.

iles hip	'reliever'	'preventer'
Frequency of repeat Rx		
Once a month	11	15
Every 2 months	3	2
Every 3 months	4	0
Rarely, less than every 3 months	8	5
[Not known]	[4]	[3]
[Not applicable]		[5]
Number of inhalers (items) per Rx		
One	16	16
Two	4	1
[Not known]	[10]	[8]
[Not applicable]		[5]

that negative views on paying also played a role. This was supported by the length and detail of conversations about views on charges (reported elsewhere<sup>25</sup>) and strategies used to manage cost (see below).

# Viewing asthma inhalers as essential, and the differential impact of cost

Whether cost featured as an influence seemed to depend on whether interviewees saw their asthma medication as essential, defining this as medication they needed to control their asthma and thus ensure a good quality of life. If they did, they felt that making cost-related choices was not an option, and they would have to find the money to pay:

"I need them [Ventolin® and Symbicort®] and they're the first and foremost thing. It's no good me not getting them, because [...] I just won't be able to breathe, so I won't be fit enough for work anyway, so they are an essential need." (ID3)

Some interviewees made comparisons with other types of medication – for example, treatment for minor ailments was seen as less essential – thus permitting cost-related decisions:

"More with the hayfever, [..] if your eyes and that are going, it doesn't matter as much as if you can't breathe. [..] Sometimes you wouldn't get them because it's expensive for hayfever tablets, but the inhalers I would always have them." (ID25)

The decision that asthma medication was essential and needed to be paid for was particularly pertinent for interviewees with affordability issues. Some explained that in order to be able to afford their asthma medication, they may have to sacrifice something else:

"It's like nineteen pound a time [...] for the three different things, so [...] an enormous amount, and if you've not got it and you need it, you really need it, I mean, when it's a choice between .. how can I put it? .. If XX (12 year old boy) needs anything, cos he's a growing lad [...]. You've gotta think, 'Well, I really need to breathe, you know, and I'm afraid you're gonna have to go without a pair of shoes. Or you're gonna go without a pair of pants. You're gonna have to wait.'" (ID6)

However, not all interviewees judged their asthma medication as essential. In the following example the interviewee distinguished between his hypertension tablets, which he did consider essential, and his asthma medication:

"I don't have the choice with the blood pressure one really. [...] If I don't take the lisinopril then I will have high blood pressure. If I don't take the inhaler I'll have asthma for a bit and then it'll go away." (ID29)

Each individual interviewee seemed to make his/her own judgement on which types of medicines they defined as essential or less essential. These judgements seemed to be based on a multitude of influencing factors: their own experience and the severity of their asthma and other conditions; experiences and practices of family and friends; information obtained from health professionals; 'official' literature such as health leaflets; magazines; or the internet.

Are both 'reliever' and 'preventer' seen as essential? When judging the necessity of asthma medication, many interviewees further differentiated between their two types of inhalers. Those who did differentiate, commonly considered the 'reliever' essential because it provided immediate relief from acute and potentially serious and distressing asthma symptoms. Several interviewees judged 'preventer' inhalers to be less essential, justifying this by the lack of immediate and clearly evident benefit. Cost thus had a differential impact on individuals' decisions to buy and use one or both types of

inhalers, and interviewees were more likely to choose to buy the 'reliever' than the 'preventer'.

Keeping use of asthma inhalers and cost to minimum Many interviewees described numerous ways through which they kept the cost of asthma medication to a minimum. Interviewees would not obtain more medication than they needed, and, once paid for, they valued it and avoided waste. One commonly used cost reduction strategy was that of 'stretching' medication, usually inhalers, to make them last longer. Some interviewees did this so that a new repeat prescription was required less often. Others ensured only one item would be due each month, i.e. they would get the 'reliever' one month and the 'preventer' the next:

"Because they are that expensive, I tend to only take my inhalers when I need 'em. [...] Like on here it might say ... 'two puffs, four times a day' or whatever it actually says, and if I do not think I need that I don't do that, because I try and make it spin out that bit longer, then I'm not asking for another repeat prescription." (ID14 - unprompted)

Cost-related 'stretching' affected both reliever and preventer inhalers. Interviewees would try and cope without their 'reliever' by avoiding known triggers or, once they were experiencing a slight attack, by using other ways of managing it, such as relaxation breathing:

"I do find because I have to pay for it I'm dead stingy with .. when I take [my Ventolin]. I'll wait to the point where I know that I have to have it. I'd rather just sit down and try and let it settle down rather than take my inhaler." (ID23)

Interviewees would cut down the 'preventer' dose they were supposed to use, or would only use it when they felt they would really need it – for example, at the start of a cold. These are behaviours commonly found in asthmatics, but several interviewees stressed that these decisions were reinforced by cost. Several interviewees knew that reducing their 'preventer' inhaler use meant that their asthma was not as well controlled as when they used their medication properly:

"You just make it last longer. Maybe not take it as it says, three times a day or whatever, just when you need it. So really, instead of taking it as a preventative, you're taking it, you're reacting to the actual symptoms, which I don't suppose is the correct way, but you just wait till you actually do get breathless." (ID37)

"When I do use my medication properly, I feel far, far better." (ID4)

#### Talking to GPs and their role

Despite describing the use of numerous strategies to reduce medication cost, interviewees generally said they would not raise issues of cost and affordability with their GP. Only a few said they had asked for a larger supply, thus getting more for the same charge, and those that did used language that suggested asking was almost deviant behaviour:

"I was dead cheeky once, when I [...] was going skiing and I only had a little bit left in one of them and I asked for two [...]. And it was a bit like you shouldn't really be doing this, because obviously for the same item you only pay once." (ID30)

When interviewees did get larger supplies it seemed that, in many cases, this had been initiated by the GP. Several interviewees felt GPs were reluctant to prescribe longer supplies due to their increasingly tight drug budgets, and that this had increased over the past years (see Table 3 for information on length of prescription and number of inhalers).

"I had a kind GP at the time and he would double up, and I think he would give me a three month supply for one charge, but I know that GPs are reluctant often to do that now, their drugs budget is probably much tighter than it used to be." (ID5)

#### Pre-payment certificates

Pre-payment certificates – which, at the time of this study cost about £33 and £91 for four and 12 months respectively – can be purchased by patients who require two or more regular items a month, thus limiting overall cost. Six interviewees had valid PPCs, six had had one in the past, and almost all of the rest (15/18) were aware of their existence. Having a PPC meant that cost and affordability were no longer an issue, and interviewees could obtain medication when required. They were generally positive about the existence of PPCs:

"You're not frightened you can't afford it." (ID7)

Not all of the interviewees who would potentially benefit had a PPC, and some had difficulty affording the lump sum payment. The often unpredictable and episodic nature of asthma meant that interviewees found it hard to anticipate when a PPC would be worth buying. When asthma is well controlled asthmatics can feel well for extended periods, thus not requiring much medication. However, they could be more prone to chest infections (for example) which may require increased use of their usual inhaler(s) and additional treatment with ICS and/or antibiotics, resulting in additional prescription charges:

"You never know how many you're actually gonna buy 'cos your asthma might be great for that year and then you don't end up buying any and it's forty pound down the drain." (ID 2)

"If you'd have known that [use of a number of different medicines] was gonna come up you'd have quite happily paid the eighty pounds." (ID18)

#### **Discussion**

This is the first qualitative study to explore, in depth, asthma

patients' management decisions in relation to the cost of English prescription charges. It thus yields valuable new insights.

Recruitment was restricted to 30 non-exempt asthmatics.<sup>22</sup> The inclusion of some exempt patients may have been useful in order to explore further the role of cost in relation to other factors affecting medication adherence. This could be addressed through the design of a survey questionnaire for distribution to a larger sample of exempt and non-exempt asthmatics, thus establishing the prevalence of affordability issues and differential use of cost reduction strategies and their impact on asthma control, in the context of standardised measures for asthma severity as well as other demographics. This might also address the potential limitation of exploring the impact that gender and age may have on patient decision-making in this context. Nevertheless, the value of the present study lies in the depth and detail that it explored.

#### **Key findings**

Many interviewees felt that they should not have to pay prescription charges for asthma medication, and for others, charges posed a more direct affordability issue. Both seemed to impact on interviewees' asthma management decisions, which was illustrated by the number of strategies interviewees employed to keep medication cost to a minimum. These related to prioritising types of treatment, rationing, substituting and postponing, as well as trade-offs with other needs. These strategies are similar to those identified in relation to other acute and chronic conditions, both in the UK<sup>20-22</sup> and further afield.<sup>26-31</sup>

Despite using cost reduction strategies and trade-offs, interviewees did not generally raise issues of prescription charge cost or affordability with their GPs, who may be able and willing to help.<sup>32</sup> Whether interviewees viewed their asthma medication as essential was influential, and those who did seemed most likely to buy and use their treatments as prescribed. Most interviewees defined their 'reliever' inhaler as essential, as this provided immediate relief from asthma symptoms. However, even though accepted as essential by some, several interviewees did not consider steroid inhalers as essential. Many reasons for this perception were not related to cost and have been identified in previous studies.<sup>10,11,33-35</sup> However, cost seemed to reinforce these attitudes.

A further important finding was that for two interviewees, cost-related underuse of their 'preventer' inhalers led to sub-optimal asthma control. This suggests that prescription charges may have a comparable negative effect on asthma control among English non-exempt patients on low incomes, as identified in several large-scale Canadian studies<sup>14-16</sup> which demonstrated that steroid inhalers were particularly affected by medication cost. The present study offers some explanations for their findings.

#### Value of pre-payment certificates

PPCs are in place to limit the amount patients have to spend on prescribed medicines. In England, they are currently available for £27.85 or £102.50 to cover treatments dispensed over the subsequent three or 12 months, respectively. They are financially beneficial for asthmatic patients receiving more than one regular item every month, yet not all interviewees who would have benefited had a PPC. Low awareness of their existence found in previous studies<sup>22</sup> was not an issue here. Some patients, particularly those on low incomes who most need protection from unnecessary expense, cannot afford a lump sum payment.<sup>22,36</sup> This has since been addressed through the introduction of a monthly direct debit payment facility for a yearly PPC.<sup>37</sup>

However, even with recent improvements, the protection mechanism intended by PPCs may be failing for episodic conditions, since patients need to predict their medication use for advance purchase. Providing a true cap on charges, where no patient has to pay more than a set annual amount towards their medication, may be a fairer approach. Keeping track of payment of individual charges should be achievable once a comprehensive electronic NHS infrastructure is implemented.

#### Conclusion

We already know that medication cost affects the use of asthma medication, and that ICS inhalers are particularly affected. 14-16,21 Only qualitative work – as in the present study – can identify the complexity that underlies these findings, thereby providing insights into how and why prescription charges impact differentially within the population of asthma patients. Affordability, but also patients' views on how essential they judge their medication to be, are important factors. The cost of prescription charges appears to reinforce the impact that these factors have on asthma patients' management decisions. As patients do not appear to raise these issues with their doctor, it may be useful for GPs and other healthcare professionals to incorporate related questions into consultations and medicines use reviews.

A deterrent effect of prescription charges on the use of essential asthma medication is against the UK Government's commitment to providing NHS treatment based on clinical need and not affordability. Furthermore, cost-related medication non-adherence may affect asthma control negatively and, ultimately, increase NHS resource use. It is hoped that this study provides further useful evidence for the still on-going review of prescription charges in England, where – unlike asthma – cancer was recently added to the list of medical conditions qualifying for charge exemption.

#### **Conflicts of interest**

No conflicts of interest

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#### Prescription charges and asthma patients

#### Appendix A. Interview topic guide.

Aim: In what ways do patient charges influence patients' decisions about how to manage their asthma (and other health matters)?

- 1. Social circumstances Work? What? Live on own / with family - who?
- 2. General health, other conditions
- 3. Your asthma: symptoms; symptom frequency; types of symptoms; severity; history: how long
- 4. What you do about your asthma? Medication. What? How use them? What known about how medication works? Views on their effectiveness and importance
- 5. What factors affect what you do about your asthma? e.g. How serious asthma is; family and friends; previous experience of asthma; family history of asthma; presence of other illness; advice from health professionals; Influence of media: magazines, TV etc.
- 6. Has how you manage your asthma changed over time? History - management changed?
- 7. Does the cost of medicines (prescription charge) influence how you manage your asthma? How important is cost in comparison with all factors considered under q. 5? Changes over time? Other medication regularly, not for asthma? - Cost implications?
- 8. In what ways does the cost of medicines influence how you manage your asthma?
- 9. Who do you talk to if / when you have problems affording your medication?
- 10. Are there some kinds of medicines you would be more willing to Are there some medicines you would not mind paying for? Which ones & why?
- 11. If the cost of your medicines went up or down (like in Wales, or just £1 or £2 per item), would it affect whether or not you take the medicines you need? How?
- 12. Views on current arrangements for prescription charges and

Possible changes to the policy – reported elsewhere<sup>25</sup>

