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'All illness is personal to that individual': a qualitative study of patients' perspectives on treatment adherence in bronchiectasis

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Abstract

Background Adherence to treatment is low in bronchiectasis and is associated with poorer health outcomes. Factors affecting adherence decisions have not been explored in patients with bronchiectasis.

Objective We aimed to explore patients' perspectives on adherence, factors affecting adherence decision making and to develop a conceptual model explaining this decision-making process in adults with bronchiectasis.

Methods Adults with bronchiectasis participated in one-to-one semi-structured interviews. Interviews were audio-recorded, transcribed verbatim and analysed independently by two researchers using thematic analysis. Data from core themes were extracted, categorized into factors affecting adherence decision making and used to develop the conceptual model.

Results Participants' beliefs about treatment, the practical aspects of managing treatment, their trust in health-care professionals and acceptance of disease and treatment were important aspects of treatment adherence. The conceptual model demonstrated that adherence decisions were influenced by participants' individual balance of barriers and motivating factors (treatment-related, disease-related, health-care-related, personal and social factors).

Conclusion Adherence decision-making in bronchiectasis is complex, but there is the potential to enhance adherence by understanding patients' specific barriers and motivators to adherence and using this to tailor adherence strategies to individual patients and treatments.

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Introduction

Low adherence to treatment is a recognized issue in the management of chronic respiratory diseases and is frequently linked with poorer health outcomes.^{1–3} We recently reported that, in a cohort of 75 patients with bronchiectasis, only 12 patients (16%) were adherent to all prescribed treatments and that non-adherence to inhaled antibiotics was associated with an increased frequency of pulmonary exacerbations.⁴ Minimizing pulmonary exacerbations is one of the key aims of bronchiectasis treatment⁵ and is a major focus for bronchiectasis research.⁶ Based on our data, enhancing adherence to treatment is important to achieve this goal. Thus, interventions to enhance adherence to new and existing treatments have potential to improve the health status of these patients.^{7–10}

Little is known about factors affecting adherence or how adherence can be improved in the bronchiectasis population. Evidence from other chronic disease populations demonstrates that no single factor predicts adherence, with many psychological theories attempting to explain this complex behavioural process.^{11–13} We previously demonstrated that beliefs about treatment were more strongly associated with adherence than clinical factors including forced expiratory volume in one-second (FEV₁) and health-related quality of life.⁴ However, this study was quantitative in nature and did not explore factors such as the practical or psychological aspects of adherence, for example, maintaining a routine for treatment or motivation to adhere. These factors are essential components of self-management decisions in bronchiectasis,¹⁴ and are therefore likely to be important factors affecting adherence. A single study in bronchiectasis used a self-management programme based on self-efficacy theory to increase patients' self-efficacy, but this did not translate into an improvement in adherence to treatment.¹⁵ A second study compared the effectiveness of nurse-led vs. doctor-led care and demonstrated an improvement in adherence to antibiotics in the nurse-led group.¹⁶ However, adherence was not the primary

outcome of either study and, in both cases, was measured using non-validated, self-reported adherence measures. Historically, behaviour change interventions, such as those for adherence have often not been theoretically based or aimed at changing specific adherence behaviours, which may have resulted in the failure of many interventions.^{17,18} A detailed understanding of adherence decision making in bronchiectasis is needed prior to the development of any intervention. The aim of this study was to explore patients' perspectives on adherence, factors affecting adherence decision making and to develop a conceptual model explaining this decision-making process in bronchiectasis.

Methods

Study design

Participants completed a single one-to-one interview with the researcher (AMcC) between November 2011 and April 2012. Ethical approval was received from the Office for Research Ethics Northern Ireland in August 2011 (11/NI/0109). Participants provided written informed consent prior to participation in the study. Prior to inclusion in this study, participants also participated in a related study and data collected as part of that study were used to categorize participants' adherence based on the answers to a modified version of the Self-reported Medication-taking Scale¹⁹ (adherent score of $\geq 80\%$, non-adherent score $< 80\%$)⁴. Participants completed a scale for three different treatment types (inhaled antibiotics, other respiratory medicines and airway clearance) and were classified as adherent or non-adherent to each treatment.⁴ Those who were non-adherent to one or more treatments were classified as non-adherent and those who reported to adhere to all treatments were classified as adherent.

Sampling of study participants

The researcher (AMcC) screened data of participants due to complete a related study⁴ from

November 2011 to select a maximum variation sample of participants in terms of age, gender, lung function, adherence status, prescribed treatments and employment status. Participants were consecutively approached and recruited in person from four hospital sites in Northern Ireland by the researcher (AMcC) prior to completion of the previous study.⁴ Recruitment of participants continued until data saturation was reached. Participants were ≥ 18 -year olds, had bronchiectasis diagnosed by high resolution computed tomography and were categorized as adherent or non-adherent according to the Modified Self-reported Medication-taking Scale.^{4,19} Participants had a history of *Pseudomonas aeruginosa* infection. Participants were excluded if they had Cystic Fibrosis (CF)-related bronchiectasis.

Data collection

Participants completed a one-to-one semi-structured interview with the researcher (AMcC) in a private room either at hospital or in their own home, depending on participant preference. Interviews were audio-recorded. Participants were asked a series of open-ended questions covering the topics shown in the outline topic guide (Table 1). This was developed based on the preliminary findings of the prospective study⁴ as well as the relevant literature in the field of treatment adherence and refined within the project team.^{14,20} The topic guide was iterative and as new themes emerged from the data, the guide was updated to reflect these.²¹

Analysis

Interviews were transcribed verbatim by the researcher (AMcC) and imported into NVivo 9[®], Warrington, UK. Participants were each given an identification code denoting their sex (M/F), interview number and whether they were adherent (A) or non-adherent (NA). Field notes were taken and used to inform the analysis. All transcripts were analysed independently by two researchers (AMcC and CH). A two-stage analysis was undertaken. Firstly, in-depth

Table 1 Outline of interview topic guide

Outline of interview topic guide
Discussion about the types of treatments that participants use for the management of their bronchiectasis.
Participants' understanding of treatment adherence in bronchiectasis.
Participants' perceived barriers and motivators of treatment adherence in bronchiectasis.
Effect of the following factors on treatment adherence in bronchiectasis:
Treatment type
Health status
Short and long-term treatment benefits
Daily routine and burden of treatment
Participants' concerns about taking medications, including dependency, side-effects, efficacy, long-term effects, self-efficacy.
The role of health care and health-care professionals in treatment adherence:
Prescribing treatments
Follow-up and monitoring of treatments.
How participants' treatment adherence could be improved including potential interventions to improve adherence

thematic analysis was completed using constant comparison within and between transcripts, with a particular focus on comparing the views of those who were adherent and non-adherent.²² A network of core themes and sub-themes was developed. Themes were condensed and re-classified throughout this process. A consensus on emergent themes was reached within the research team. Data saturation was reached once no further new themes emerged and recruitment to interviews ceased.²¹ Secondly, factors influencing adherence and their relationships to each other were extracted from the core themes and used to develop a conceptual framework to explain the decision-making process around adherence to treatment in bronchiectasis.²²

Results

Participants were approached consecutively; two declined to participate as they did not wish to be interviewed and 16 agreed to participate, at which point data saturation was reached. Interviews lasted a mean of 48 min (range 19–79 min). Participants were predominately

middle-aged females, with moderate impairment in lung function;²³ 63% were prescribed inhaled antibiotics, 94% were prescribed other respiratory medicines and 100% were prescribed an airway clearance regimen (Table 2). Eight participants (50%) were categorized as adherent and 8 as non-adherent overall. Characteristics of adherent and non-adherent participants are shown in Table 3. Four core themes emerged with contributing subthemes: beliefs about treatment, practicalities of treatment, trust in health-care professionals and acceptance of disease and treatment; these are summarized in Fig. 1.

Table 2 Participant characteristics

Participant characteristics	Result (<i>n</i> = 16)
Mean age (range), years	65 (52–73)
Gender M/F, <i>n</i> (%)	6 (37)/10 (63)
Mean (range) FEV ₁ , %	56 (35–88)
Prescribed inhaled antibiotics, <i>n</i> (%)	10 (63)
Prescribed other respiratory medicines, <i>n</i> (%)	15 (94)
Prescribed airway clearance, <i>n</i> (%)	16 (100)
Adherent to inhaled antibiotics, <i>n</i> (%)	5 (50)
Adherent to other respiratory medicines, <i>n</i> (%)	13 (87)
Adherent to airway clearance, <i>n</i> (%)	11 (69)
Employment status, <i>n</i> (%)	
Employed or self-employed	2 (13%)
Retired	14 (87%)

M/F, male/female; FEV₁, forced expiratory volume in one-second.

Participant characteristics	Adherent	Non-adherent
Mean age (range), years	66 (52–74)	64 (55–73)
Gender M/F, <i>n</i> (%)	3 (37.5)/5 (62.5)	3 (37.5)/5 (62.5)
Mean (range) FEV ₁ , %	54% (35–76)	58% (24–88)
Prescribed inhaled antibiotics, <i>n</i> (%)	4 (50)	6 (75)
Prescribed other respiratory medicines, <i>n</i> (%)	8 (100)	7 (88)
Prescribed airway clearance, <i>n</i> (%)	8 (100)	8 (100)
Adherent to inhaled antibiotics, <i>n</i> (%)	4 (100)	1 (17)
Adherent to other respiratory medicines, <i>n</i> (%)	8 (100)	5 (71)
Adherent to airway clearance, <i>n</i> (%)	8 (100)	3 (17)
Employment status, <i>n</i> (%)		
Employed or self-employed	2 (25)	0 (0)
Retired	6 (75)	8 (100)

Table 3 Characteristics of adherent and non-adherent participants

Core themes

Beliefs about treatment

All participants reported making judgments about their need for treatment based on perceived benefits of treatment, for example, symptom reduction or fewer exacerbations.

'I really have to do it... I get blocked up if I don't do it (airway clearance).' (F7A)

Non-adherent participants tended to stop treatments when they perceived themselves to be well, with few symptoms.

'If I don't feel I've got it (mucus), I don't use the Acapella® (a hand-held device used to assist with the clearance of excess mucus from the airways).' (M5NA)

Adherent participants had stronger beliefs about the need for treatment and placed less emphasis on concerns about long-term effects of medication compared to non-adherent participants. Non-adherent participants' concerns reflected a strong belief that medicines were intrinsically harmful.

'I just feel that, honestly, the more stuff you put into yourself... is it doing you more harm than good?' (F9NA)

However, the majority of adherent participants also had concerns, mainly about antibiotic resistance, dependency and side-effects, but

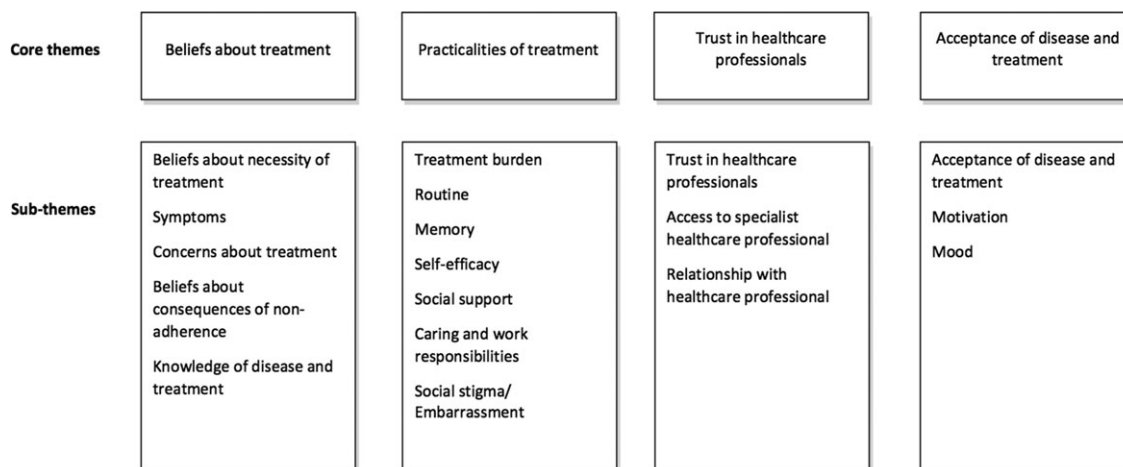


Figure 1 Summary of interview core themes and subthemes.

these concerns were not enough to stop them taking a treatment.

'I think the more antibiotics you would take...you would get used to them and they maybe would be less effective.' (F13A)

In general, adherent participants had insight into the potential negative consequences of non-adherence; some non-adherent participants also demonstrated this.

'I feel if I keep my medication right and keep doing it every day that maybe I'll prevent things from getting any worse.' (F15A)

However, a minority of non-adherent participants had no insight into the consequences of poor adherence and did not perceive it to be a problem.

'I don't really need an antibiotic...it doesn't annoy me that much not taking it.' (M3NA)

All participants had a basic understanding of the purpose of treatment, particularly airway clearance; however, it was clear that some participants (both adherent and non-adherent) were misinformed about the purpose of and mechanism of action of their treatments and that this informed beliefs about treatment.

'I always assumed I would be feeling great... I don't seem to breathe any easier with taking them.' (F11NA)

Disease knowledge varied amongst participants. Knowledge about disease was cited as a motivator for the majority of participants whilst for a minority of non-adherent participants, a lack of disease knowledge was perceived as a barrier.

'I think the more you know about your disease, the better you understand why you have been prescribed certain drugs...then you would be more likely to take them.' (M8NA)

'I think if you know the answer to the problem (adherence), the problem isn't as big.' (F4NA)

However, four participants (three adherent, one non-adherent) did not want to know any more about their disease and its progression.

'I've never really wanted to know too much. I don't need to know what my lungs look like or I've no desire to see specimens... I don't want details.' (F12A)

Practicalities of treatment

For all participants, treatment burden (i.e. the length of time and inconvenience associated with treatment) was perceived to be higher for inhaled antibiotics and airway clearance, compared to other inhaled and oral treatments.

'It's inconvenient to mix it up (inhaled antibiotics) and leave it to settle and maybe you're going out somewhere, you're in a hurry and you forget it, 'I'll leave it until later on... I'll do it when I

come back,' never do it when I come back.'
(M3NA)

Adherent participants described how they managed this burden by building treatments into their daily routine, whilst non-adherent participants perceived the time and complexity of these treatments to be unmanageable and had no set routine to complete these treatments.

'(Doing treatments is) as much my routine as taking breakfast or having my shower...it's just part of the day.' (F10A)

Non-adherent participants cited ageing and poor memory as barriers to adherence. In contrast, adherent participants stated having reminder strategies and maintaining their routine overcame this barrier.

'I think especially as you get older that you need to be reminded of things.' (F9NA)

Participants generally had confidence in their ability to do treatments; however, a minority of non-adherent participants reported that they lacked confidence in their ability to complete airway clearance.

'I do do it myself but I don't feel it's as good as, em, someone doing it for you.' (F6NA)

Family support was viewed by both adherent and non-adherent participants as being beneficial to encourage adherence, by acting as a reminder and assisting with airway clearance. However, several participants also noted that they did not want to be a burden on their families.

'You know they (family) never rush me or nothing like that...they understand...that I have to take them (treatments).' (M16A)

Caring and work responsibilities were generally viewed as barriers to adherence. Two non-adherent participants were struggling to care for family members and manage their own condition, whilst the majority of participants recognized that adhering to treatment would be more difficult if working.

'If I worked or anybody worked...you couldn't do it (inhaled antibiotic), unless you were wonder woman or something.' (F11NA)

However, two adherent participants worked part-time and stated that they built their treatments into their routine. Fatigue was also cited as a barrier for evening treatments of inhaled antibiotics and airway clearance.

Participants' recurrent cough and expectoration of sputum due to bronchiectasis was perceived by both adherent and non-adherent participants to be associated with a degree of social stigma and embarrassment. Some adherent participants reported that they completed treatments prior to going out, as a way of avoiding embarrassment in social situations, by minimizing sputum expectoration and coughing in public.

'I don't want to be trying to cough and not be able to get rid of my sputum...so that's why you would do it (airway clearance) before you would go out.' (F13A)

Participants avoided social situations when unwell and concealed treatments from others to avoid embarrassment.

Trust in health-care professionals

Participants generally reported having good relationships with health-care professionals, particularly specialists and that they trusted their health-care professionals to prescribe appropriate treatments for them.

'You're only a human being and the professional's away above you and they know the best what to do and what not to do.' (M1A)

For non-adherent participants, this trust was balanced against their own beliefs and perceptions when making adherence decisions.

'They're trying to keep you as well as possible (health-care professionals) and if I can do that without having too many side-effects I will do it (take medication).' (F2NA)

Specialist health-care professionals were viewed as being more appropriate than general practitioners (GPs) for managing bronchiectasis.

'I think as far as my respiratory problems are concerned it's all basically handled by the (hospital name)...the GP, eh, would only come into it if I need an emergency.' (M14A)

Time with and regular review by specialist health-care professionals were felt to facilitate adherence by increasing confidence in ability to manage the condition.

'If I go to see a doctor, I have questions and I want answers...and it's nice that they have a minute to sort of explain something.' (F10A)

Participants wanted more access to physiotherapy, with non-adherent participants reporting that this would facilitate adherence.

'I think people who find difficulty (with airway clearance) should get more help from the physios.' (F2NA)

A minority of non-adherent participants cited poor GP relationships as a barrier to adherence, particularly when requesting access to rescue antibiotics (2-week course of antibiotics to be kept at home and initiated at the start of a pulmonary infection).

'I have often been refused an antibiotic...maybe at a push they'll give it to you for a week but you know it's not going to, em, do you the same amount of good as having it for 14 days.' (F6NA)

Acceptance of disease and treatment

Participants generally accepted their disease and treatment as part of their everyday life. Bronchiectasis was accepted as requiring long-term management and adherence was viewed as preventing further deterioration in health and maintaining quality of life.

'I accept that I have this chest problem and, eh, it needs to be treated and monitored.' (M14A)

'I know I'll never get better. I just hope I don't get much worse which I, em, probably will do but I can do nothing about it, eh, except keep taking the medication and listening and doing as the doctors tell me.' (M8NA)

However, two non-adherent participants appeared to be struggling to accept their bronchiectasis which they linked to feeling 'down' (F11NA) and acted as a barrier to adherence.

'I was coping more than well (with bronchiectasis). I don't cope so well now with it...if I didn't know better I'd say I was depressed.' (F4NA)

Adherers recognized it as their own responsibility to cope with and manage their treatment.

'What more can a doctor do, call round every morning and give them a spoonful? No. I mean, be realistic, you know. The state looks after people extremely well, surely they can do a little bit for themselves (laughs).' (F4NA)

Non-adherers also accepted that it was their own responsibility to manage their condition, but this was not sufficient to adhere.

'I expect people to help me (manage my disease) but I'm not putting enough effort in and I know I'm not.' (F4NA)

Factors affecting adherence decisions

Five factors affecting adherence were extracted from the core themes described: treatment-related factors, disease-related factors, health-care-related factors, personal factors, and social factors (Fig. 2). A conceptual model of adherence decision making in bronchiectasis was developed from these factors and illustrates the barriers and motivating factors which affect this decision-making process (Fig. 2). Barriers and motivators were not put into a hierarchical order of importance as the relative importance was individual to each patient.

'All illness is personal to that individual'. (M5NA)

The model shows that participants balanced an individual combination of factors against each other to make the decision to adhere or not to adhere, a so-called 'cost-benefit analysis'. Based on this concept, costs were considered to be 'barriers to adherence' and benefits were 'motivators to adherence.' This cost-benefit analysis is demonstrated through the examples below. In the first example, whilst the participant was aware of the benefits of treatment (treatment-related) as a motivator to adherence, the burden and the amount of time that treatment took to complete (treatment-related), coupled with the participant's apathy towards treatment (personal) was too great a barrier and the participant decided not to adhere to treatment.

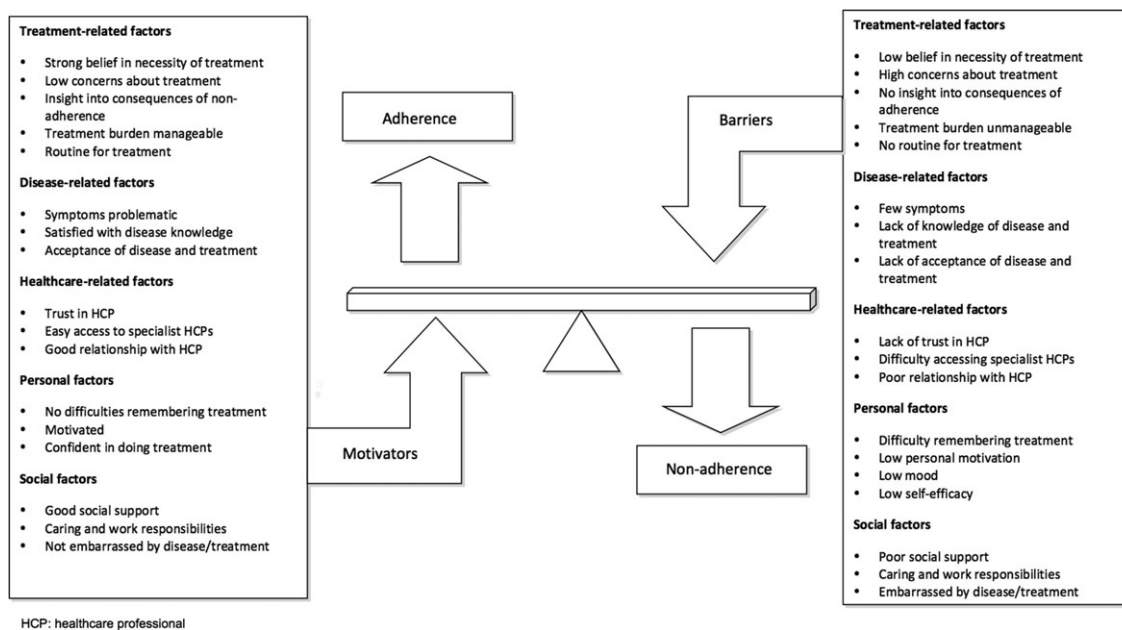


Figure 2 Conceptual model of adherence decision making in bronchiectasis.

‘Sometimes, I just can’t be bothered (taking inhaled antibiotics) and I know I should... I do feel better, overall, when I take it and I know I need to take it. But I just, sometimes, just can’t be bothered at night time going through the whole rigmarole.’ (F11NA)

In contrast, motivators to adherence, that is, necessity of treatment (treatment-related) outweighed barriers due to health-care professionals positively reinforcing the need for treatment (health-care-related) and led the participant to adhere, as illustrated below:

‘I’ve been taking it (inhaled antibiotics) this good while and to be quite honest with you, I don’t think it’s, it’s doing the job it’s supposed to be doing...I have queried that with (specialist nurse’s name) but she informed, told me, yes, that it would be essential for me to take it.’ (M1A)

Discussion

This is the first study to explore patients’ perspectives on adherence, factors affecting adherence and to develop a conceptual model explaining this decision-making process in bronchiectasis. We have shown that patients’

beliefs about treatment, the practical aspects of managing treatment, their trust in health-care professionals and acceptance of their disease and treatment are all important aspects of treatment adherence in bronchiectasis. We have demonstrated that adherence decision making is complex, involving many barriers and motivators to adherence and as shown in our conceptual model, patients weighed up an individual combination of barriers and motivators to adherence. It is also evident that there are common barriers and motivators cited by patients that could be the target of an adherence intervention in bronchiectasis. Therefore, future work should focus on developing strategies that specifically target the barriers identified.

We extracted factors affecting adherence from the core themes described by participants and found that the barriers and motivators identified were nearly identical to those reported in CF²⁰ and similar to those previously reported in bronchiectasis^{4,14} and chronic obstructive pulmonary disease.^{24,25} Beliefs about treatment played a key role. Participants balanced their perceived need for a treatment

against what they perceived to be the potential harm or burden of that treatment. Similar to the findings of this study, a synthesis of 37 qualitative studies exploring adherence to treatment in chronic disease, found that participants appraised the benefits of their medicines whilst also evaluating the potential harm that their medicines could cause.²⁶ We have also highlighted that beliefs about treatment are associated with treatment adherence, with those who had high concerns about medication and low necessity for airway clearance less likely to be adherent.⁴ Knowledge about disease and treatment was shown to influence beliefs about treatment and there were clear gaps in participants' knowledge; however, this was true for both adherent and non-adherent participants. Thus, knowledge alone is not enough to adhere to treatment²⁷ and any potential intervention should be individualized to each person's preference including the level of information they wish to receive.

Similar to CF, treatment burden and difficulty maintaining a routine were important barriers to adherence for airway clearance and inhaled antibiotics.²⁰ This reflects our recent findings, in that, those who were prescribed more medications were less likely to be adherent to inhaled antibiotics.⁴ Both adherent and non-adherent participants were prescribed similar treatments; therefore, it is likely that those who are non-adherent experience more difficulty managing their burden of treatment as illustrated by non-adherers having fewer strategies in place to assist adherence, such as having an organized routine for treatment. In addition, a few non-adherers discussed how their wellbeing influenced their perceived treatment burden, such as when fatigued or when experiencing low psychological mood. Embarrassment and social stigma associated with sputum and coughing due to bronchiectasis was noted. This could be due to perceptions that the expectoration of sputum was socially unacceptable, as has been reported in CF²⁸ and this belief may have been reinforced by recent large-scale public health campaigns about infection control.

Trust in health-care professionals is vital to decision making in chronic disease²⁹ and participants expressed an inherent trust in health-care professionals, particularly specialists. Access to and time with specialist health-care professionals were motivators to adherence, as has been reported in CF.²⁰ Participants generally expressed satisfaction in their relationships and interactions with health-care professionals but some non-adherent participants reported difficult relationships with GPs, indicating a potential target for future adherence interventions. Social support from family was viewed as facilitating adherence to treatment,²⁰ but some patients did not want to be a burden on their family, meaning that patient preference is important when deciding whether to include family members in their management.

We have shown that participants were generally accepting of their condition and its treatment. Managing bronchiectasis was viewed to be a part of daily life and to be something that was lifelong. Motivation and self-efficacy are important components of several health behaviour theories.^{11,12} We reported that motivation and self-efficacy were generally high but that some non-adherent participants were apathetic towards treatments and lacked confidence in their ability to undertake airway clearance as has been previously reported for self-management.¹⁴

Cost-benefit analysis is the foundation of several social cognitive theories explaining adherence behaviour^{30,31} and also appears to be the basis of adherence decision making in bronchiectasis. Participants' decisions were individual but influenced by commonly cited barriers and motivators; therefore, interventions to enhance adherence will be complex and multicomponent. These complex interventions should be theoretically based and involve patients in their development.^{17,18,27} To ensure the intervention is effective, we need to map these findings onto existing psychological frameworks, such as the Theoretical Domains Framework³² and use this approach to allow us to identify behavioural change techniques that are directly informed by the underlying behaviour.³³

Limitations

Views were obtained from a diverse range of patients with bronchiectasis and history of *P. aeruginosa* infection. Approximately 20% of patients with bronchiectasis in the United Kingdom are infected with *P. aeruginosa*.⁵ These patients are known to have poorer lung function and quality of life than those without *P. aeruginosa*.^{34,35} Semi-structured interviews gave participants the opportunity to offer a detailed account of their views on a one-to-one basis.²² The rapport built up between the researcher and participants through the previous study contributed to the quality of data collected via interviews. It is possible that involvement in the previous study may have made patients more aware of adherence. However, issues with adherence were not discussed in detail prior to the interview and therefore, it is unlikely to have affected the data obtained. Self-report is known to overestimate adherence in bronchiectasis.⁴ However, in this study, as the data generated were based on patient perceptions, it was relevant to classify them based on self-reported adherence.

Conclusion

This study has shown that adherence decision making in bronchiectasis is complex, but that there is the potential to enhance adherence by understanding patients' specific barriers and motivators to adherence and using this to tailor adherence strategies to individual patients and treatments. Therefore, future research should focus on the design and efficacy of a bronchiectasis-specific adherence intervention that can be tailored for each patient and ultimately be used in clinical practice.

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Conflict of interest

AMcC, MT, JB and CH have no conflict of interests. SE has received consultancy fees paid to Queen's University Belfast by Gilead Sciences, Novartis and Forest.

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