DANISH MEDICAL JOURNAL

Original Article

Patient perspectives on barriers to optimal asthma control in Danish respiratory specialist practice

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Dan Med J 2025;72(11):A03250213. doi: 10.61409/A03250213

ABSTRACT

INTRODUCTION. Although well-documented asthma treatments are available, many patients with asthma remain symptomatic, even when managed by respiratory specialists. We aimed to describe barriers to optimal asthma management in Danish respiratory specialist practice.

METHODS. This was a qualitative study of 20 patients (mean age 37.6 years, six 40+ years; 17 women) with asthma from two specialist practices, with interviews conducted by phone.

RESULTS. Many patients were unaware of the timeline for their course of treatment or what it entailed to be a patient in a pulmonary clinic, including being uncertain about how many consultations they were entitled to, the agenda of the next appointment and what the exact goals of the treatment were. Patients expressed doubts regarding the dosage and effectiveness of their medication. Some questioned whether they were taking their medication correctly and whether it was acceptable to take additional doses. Patients reported that they occasionally forgot to take their medication because they had not established a consistent routine for it.

CONCLUSIONS. Barriers were often quite practical and simple, and can most likely be broken down by focusing on simple behavioural aspects rather than by providing more information.

FUNDING. This study was funded by Fonden for Faglig Udvikling i Speciallægepraksis, Danske Regioner.

TRIAL REGISTRATION. Not relevant.

Asthma affects 300 million people globally [1], and approximately 430,000 are being treated for asthma in Denmark. Their average age is 40 years (37% being less than 40 years), and 1:8 had at least one hospital contact in 2017 [2]. Few patients, even with severe asthma, are seen by a specialist [3], and distinct socioeconomic bias exists in referral to specialists, even in the Danish setting with free healthcare [4].

The Global Initiative for Asthma states that 1) effective asthma management requires a partnership between the person with asthma and their healthcare providers, 2) teaching communication skills to healthcare providers may lead to increased patient satisfaction, better health outcomes and reduced use of healthcare resources and 3) the patient's ability to obtain, process and understand basic health information to make appropriate health decisions should be considered [1].

One of the main challenges to successful asthma management is adherence to inhaled controller medications [5,

6]. The issue of poor adherence is unlikely to be solved by using inhaled corticosteroids (ICS) as part of reliever therapy, as under-use will still lead to poorer treatment outcomes.

As stated earlier, most asthma patients in Denmark are managed by general practitioners. If in doubt about their diagnosis or management, they can refer to either hospital outpatient clinics or an experienced practicing specialist. Although it might be assumed that these patients would be particularly motivated to achieve optimal control, it is still perceived that a significant proportion of patients do not have fully well-controlled asthma.

In this study, we explored barriers to optimal asthma control as perceived by patients in Danish respiratory specialist practice.

Methods

To identify reasons for poor asthma control, with a focus on adherence to inhaled medications, we designed a qualitative study with interviews of patients in two specialist clinics. Qualitative interviews are well-suited for exploring informants' perspectives, experiences and understandings of a subject [7].

We set out to include 20 patients aged 18-40 years. However, early in the study, we decided to include a few patients older than 40 years to supplement younger patients' statements; we ended up including six (out of 20) patients older than 40 years. Other inclusion criteria were symptoms of variable breathlessness, a diagnosis of asthma based on either significant reversibility to 400 µg salbutamol (increase in forced expiratory volume in the first second (FEV1) of 15%, at least 400 ml) or a positive mannitol or methacholine challenge (the latter with PD_{20} < 900 µg methacholine), and informed consent. We excluded patients with > 10 pack-years, significant comorbidities (based on the investigators' judgement, e.g. fixed airflow limitation believed not to be the result of chronic asthma), and significant language barriers.

The individual qualitative interviews followed a semi-structured interview guide that focused on the patients' knowledge of and attitudes towards asthma and medication, along with their treatment expectations (see Supplementary Material). Questions were open, allowing the patients' stories and experiences with asthma to direct the course of the interviews. The interview guide was developed by MB-H in collaboration with the clinical team. Patients were interviewed shortly after their second or third clinic visit. They were interviewed when their asthma was stable. The interviews lasted 35-55 minutes and were conducted by phone by FP and IV. The interviews were digitally recorded and transcribed verbatim. The empirical material, consisting of interview transcripts, was analysed in accordance with general principles of qualitative research [7, 8]. We conducted a thematic analysis and initially - by means of identifying codes, patterns and categories within the interview transcripts - MB-H coded and organised the various factors believed to affect medication adherence. This coding was used for selecting recurring themes that were listed, compared internally and discussed within the research group.

Trial registration: not relevant.

Results

We interviewed 17 women and three men, with an average age of 37.6 years; six were older than 40 years. More patient details are shown in **Table 1**. None of the patients were believed to suffer from dysfunctional breathing. The analysis ended up with the following three overall themes that illustrate barriers to optimal asthma control in specialist practice: 1) Uncertainty about the course of treatment in the specialist clinic, 2) Experienced effect of treatment and 3) Adherence and creating routines.

TABLE 1 Patient characteristics.

Patient no.	Age, yrs	Gender	Astma, duration since diagnosis	Family history?
1	24	F	> 6 mos.	No
2	26	F	> 6 mos.	No
3	Approx. 75	F	> 6 mos.	No
4	70	F	> 6 mos.	Yes
5	20	F	> 6 mos.	Yes
6	-	F	2 yrs	Yes
7	45	M	Since childhood	N/A
8	53	F	Approx. 1 yr	Yes
9	39	F	> 6 mos.	Yes
10	27	F	> 6 mos.	Yes
11	38	F	15 yrs	Yes
12	40	F	Approx. 25 yrs	Yes
13	31	F	> 6 mos.	No
14	32	F	> 6 mos.	Yes
15	29	M	2-3 yrs	No
16	39	F	Since childhood	No
17	41	F	Since childhood	Yes
18	-	M	-	-
19	51	F	Approx. 3 yrs	No
20	32	F	Approx. 6 yrs	No

F = female; M = male.

Uncertainty about the course of treatment

Overall, we found that what may be obvious to the physician is often far from apparent to the patient. Few patients were aware of how long they could be followed or what they should expect from being referred to the specialist.

"I mean, he is really nice, I think, and a very welcoming person... I mostly think that he is very good at explaining things, but you know, in a way like all doctors are, where you understand 50-60%, you know; something is always lost in translation". (Patient 13)

Patients were unaware of the timeline for their treatment at the specialist clinic or what being a patient in a pulmonary clinic involved. Additionally, several patients were uncertain about how many consultations they were entitled to, the agenda of their next appointment and what their treatment goals were. The patients reported experiencing uncertainty and confusion, particularly when their visits were coming to an end.

"... but it was like, now we are concluding the course [of treatment] – you know, I felt a bit like, have we even started it? I don't know, maybe it's a strange detail to notice, but still...". (Patient 13)

Some patients would have liked to be scheduled for an appointment with their general practitioner after completing their treatment at the pulmonary clinic to ensure a coherent course of treatment in the specialist

clinic. Another patient suggested implementing a follow-up programme to ensure that patients know where to seek assistance if they experience recurrence of symptoms.

"I sometimes feel that patients are discharged rather quickly when visiting a specialist. However, part of this is due to the follow-up being managed by one's general practitioner. But what does that entail exactly? It would be beneficial if there were a consistent approach to patient discharge. For instance, when a doctor states, 'your asthma is now under control,' it would be advantageous to implement a follow-up programme with the patient's general practitioner". (Patient 17)

Several patients mentioned having waited several months for an appointment with a specialist. This often resulted in consultations focusing exclusively on the patients' immediate challenges and not on what would occur moving forward - specifically, after a suitable treatment had been identified in collaboration with the specialist. Based on this, it is recommended that patients be informed about the overall course of their specialist treatment and that the timeline for the process be explicitly communicated.

Experienced treatment effect

Several patients expressed doubts regarding the dosage and effectiveness of their medication. Some wondered if they were taking their medication correctly and whether they were allowed to take extra doses. Others reported a lack of relief from the medication and, as a result, refrained from using it. Additionally, some patients were uncertain about the potential long-term impact of taking - or not taking - medication on their lives with asthma. Some patients did not perceive a direct, noticeable difference in their health owing to the medication.

Interviewer*: "Yes, and on the days, you remember to take it, do you notice any difference?"*

Patient: *"Not that I've noticed yet. I think I might need to take it more consistently to notice a difference".* (Patient 2)

Thus, feeling the effects of the medication served as a motivating factor.

"Because I really tried it, I would say – actually, I would say that after my last visit with the doctor, it really dawned on me, even though it was brief, that my lungs had indeed improved. It made me realise that it is absolutely essential to take the medication". (Patient 3)

However, not only patients who do not notice a significant difference may forget to take their medication. A patient said:

"Personally, I always think that when I feel unwell, I take medication because I want to experience its effects. And then when I feel well, I quickly forget that I had felt unwell... So that's also why I have some days when I miss taking it, because I forget. Because I don't feel the need for it in the same way". (Patient 13)

For some patients, motivation for taking the medication hinged on feeling and being aware of the consequences of not taking it.

"For me ... well, I ... I think for me, it is about knowing the consequences; I need to understand the consequences at the other end". (Patient 11)

Adherence and creating routines

Patients reported that they occasionally forgot to take their medication because they had not established a consistent routine for it. Several patients reported that they needed to keep their medication in visible locations to ensure they remembered to take it. As a result, in the interviews, several patients reflected on how medication could become integrated into their daily routines. For instance, some mentioned always carrying an extra inhaler in their bag and incorporating medication use into their morning and evening routines, such as brushing

their teeth or applying makeup. Some patients reported that flexibility in medication intake – being able to take the medication as needed – increased their adherence.

"Well, no, I would say, the first medication I received, I had to take it twice a day, morning and evening, and there was definitely a day or two that I missed. With the second medication I have now, I need to take a dose in the morning, or a puff in the morning, and then I can manage throughout the day if I feel the need to take an extra dose. So, this flexibility makes me remember it a bit more, I think. It can be easy to miss when you have to take something regularly, but if you can manage it yourself a bit, I find it easier to comply". (Patient 10)

The findings also suggest that significant changes in patients' daily lives, such as the loss of a close relative, can disrupt medication adherence, even when it was previously established as a routine.

Discussion

In our qualitative study, patients with asthma and respiratory symptoms, referred to a respiratory specialist and motivated for treatment, still faced challenges in achieving optimal asthma management. Sufficient information, a comprehensive and understandable dialogue with health professionals and optimal adherence to inhalers are all factors frequently mentioned in asthma guidelines, but are apparently difficult to achieve – also in Danish specialist practice.

Are our findings generalisable? It is, of course, possible that the practice of JV and LF differs from that of other clinics in Denmark and elsewhere. However, both specialists are experienced and take an interest in patient communication. Our patients were selected exclusively on the inclusion criteria and their willingness to participate. We did, however, end up with more women than men and noted that the participants were likely better educated than the average asthma patient. The gender difference was most pronounced, reflecting that women generally use the health system more than men [8].

Our findings do not differ much from those of previous qualitative studies, although most of the previous studies focused on inhalers and adherence only [9, 10]. A recent study from Swedish general practice also found that inadequate information or education for patients led to knowledge gaps about both disease and the effect of medicines. Interestingly, it also highlighted the importance of patients being aware of what to expect from their healthcare visits [11]. When discussing sector transition in healthcare, we often consider hospitals, general practitioners and municipal healthcare, but apparently, more can also be done in “smaller” transitions; i.e., from general practice to specialist practice.

What have we, as clinic health professionals, learned? First, we should adopt a humbler view on what can be achieved in a busy specialist clinic within a Danish healthcare setting. Second, we now know that some easily defined points for improvement can be tested/implemented in any setting. We wish to change our practice towards less information per visit in exchange for more behaviour-oriented advice, as well as better information about what will happen during the six visits that a referral from general practice allows. Asthma action plans are often suggested as an appropriate tool to reduce the risk of poor asthma control. They are often based on a traffic light indicator of asthma control, and there is evidence supporting their use [12]. However, implementation of their use is limited for several reasons [13], and our patients mainly expressed a wish for more personalised information. We therefore wish to develop a small information folder with information on treatments and actions specific to each patient, and to rearrange our waiting room to provide a few simple illustrations along with notepads and pencils for questions. We are convinced that these simple measures may also be implemented in other settings and specialities.

Conclusions

Multiple barriers exist to optimal asthma care in specialist practice. These go beyond basic information and inhaler adherence, including challenges in care sector transfers and improved management plans.

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Accepted 13 August 2025

Published 15 October 2025

Conflicts of interest CSU reports financial support from or interest in Company AstraZeneca, Company Boehringer Ingelheim, Company Sanofi Genzyme, Company Berlin-Chemie Menarini, Company Novartis, Company GlaxoSmithKline, Company TEVA, Company Orion Pharma, Company TFF Pharmaceuticals, Company Pfizer, Company Chiesi, Company Covis Pharma, Company Takeda, Company IQVIA, Company Novo Nordisk, Company Hikma Pharmaceuticals, Company Roche, European Respiratory Society. JV reports financial support from or interest in Company Fonden for Faglig Udvikling i Speciallægepraksis, Danske Regioner, Company AstraZeneca, Company Chiesi, Company GSK, Company Sanofi, Company ALK, Company GSK, Company Teva. All authors have submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. These are available together with the article at ugeskriftet.dk/dmj

References can be found with the article at ugeskriftet.dk/dmj

Cite this as Dan Med J 2025;72(11):A03250213

doi 10.61409/A03250213

Supplementary material: a03250213-supplementary

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