ORIGINAL CONTRIBUTION

Catarrh - The patient experience*

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SUMMARY Background: No study to date has looked at the symptoms of chronic catarrh as defined by the patients themselves. We looked to explore the catarrh experience through the eves of patients using a qualitative approach. Methodology | Principal: Forty-eight patients referred to Secondary Care with chronic catarrh, postnasal drip or persistent throat clearing completed an open-ended questionnaire from which a comprehensive symptom list was generated. Nineteen of these patients undertook semi-structured interviews to explore symptomatic themes relating to their catarrh using grounded theory analysis. **Results**: A standardised list of 38 catarrh-related symptoms was generated covering a wide topography. A common theme amongst interviewees was the frustration of being unable to expectorate mucus rather than expelling too much. Conclusions: Difficulties exist in establishing whether the extensive list of symptoms associated with catarrh is a result of differing experiences for patients or simply differing lexicon describing the same experience. Many of these symptoms are not included in the most commonly used noselthroat symptom instruments. Furthermore a distinction should be made between patients with true rhinitis who expel mucus and those who present with apparent postnasal drip or throat clearing but who cannot expectorate, whose management ought be focused more on symptom-coping strategies rather than medication or investigation. Key words: catarrh, postnasal drip, symptom, list, questionnaire

INTRODUCTION

Despite its use over the centuries, the term catarrh continues to elude meaningful definition and so carries with it an ambiguity when being used as a term during medical consultation ^(1,2). This renders it of little use to the clinician in diagnosis making and management planning. Furthermore, there is conspicuously little research in the medical literature to guide clinicians on the optimal management of chronic catarrh patients. Our previous work has suggested that rhinological investigations are no more yielding in chronic catarrh patients than in the general population ⁽³⁾ and that catarrh patients score highly on a number of disease-specific symptom reporting questionnaires and with similar symptom frequency to patients who have those specific conditions (4) implying that catarrh may be heterogenic in origin. Monkhouse et al. (2) reported close agreement between catarrh patients and non-catarrh patients regarding the symptomatology of catarrh, but used a physician-derived symptom list to deduce this, which risks both exclusivity and prompting of symptom reporting. We conducted this qualita-

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tive study to gain an insight into precisely what chronic catarrh patients are describing when they seek help for their problem and to explore the range of symptoms experienced in relation to their presenting problem.

METHODS

Setting, ethics and subjects

The study was conducted in the Ear, Nose and Throat outpatient department of a tertiary referral centre in the North-East of England with full ethical approval from the Local Research and Ethics Committee. All consecutive patients attending a dedicated nasal research clinic for patients referred with a primary complaint of chronic catarrh, postnasal drip or persistent throat clearing were enrolled in the study over a 2 year period. We excluded those patients who had an organic cause for their symptoms apparent on nasendoscopy in order that our sample represented those patients who present with an apparent excess of mucus in the absence of demonstrable signs of the same. Included subjects were asked to complete an

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open-ended questionnaire listing the symptoms they associate with their presenting problem, prior to their consultation. We also recruited a maximum variation sample (by age and sex) of 20 of these patients to re-attend for an in-depth semi-structured interview about their catarrh.

Analysis

On completion of the open-ended questionnaires, the direct patient responses were loosely translated into a more standardised list of symptoms. This allowed easier comparison and correlation of symptoms across patients and was done, wherever possible, without any assumption about what the patient had intended to say. Where responses appeared ambiguous they were left verbatim. The standardised lists from all patients were collated into a single cumulative list of catarrh-related symptoms and ranked in order of frequency. Once the symptom pool was becoming evidently saturated, this extensive list of symptoms was contracted by the grouping of symptoms, which, in the opinion of the two authors, were deemed to be referring to a similar problem. Symptoms in close topological relation to the presenting complaint (i.e. the nasopharynx) were generally kept discrete and those more distant to the area in question were more loosely clustered together. This inevitably introduces a degree of blunting of the list but was felt to be necessary for the list to be both meaningful and manageable. All symptoms, which were mentioned by 2 or more patients were retained in the list. By way of further validation, data collection was continued prospectively with each new patient's responses either being matched within the pre-existing list or generating a new item.

The semi-structured interviews were conducted by the primary investigator, and were recorded and transcribed to give a verbatim account of the patient's narrative. It was made explicit to patients that the interview was for research purposes only and that no treatments or interventions would result from it. Analysis of the transcripts proceeded alongside the ongoing data collection, through a process of coding and categorisation with a view to the generation of grounded theory, according to the principles outlined by Glaser and Strauss ⁽⁵⁾. This 'constant comparison' approach allows for emergent theories and areas of interest to be more thoroughly explored in consequent interviews - this is one of the guiding principles of grounded theory.

RESULTS

It was felt that the patient-derived symptom pool was becoming saturated after 48 patients had completed their open-ended symptom questionnaire. The initial cumulative standardised list of 81 items was refined through the grouping of similar symptoms resulting in a more manageable 36-item list. Consequent data collection from a further 46 subjects generated only 2 new symptoms listed by 2 or more patients, thus the final list of symptoms relating to catarrh stood at 38 items (Table 1). There was a wide variation in the topography of these symptoms including the eyes, ears, stomach and lungs. Nineteen out of the 20 patients invited for interview attended with one declining on the grounds of time constraints. Subjects had a mean age of 56.1 years (range 40 - 71 years) with a male to female ratio of 1:3. Ninety percent of subjects were nonsmokers. The data generated from the 19 interviews proved to be sufficient for the purposes of this study as both codes and categories became rapidly saturated as analysis proceeded.

When asked about their presenting problem, a majority of the interviewees likened their symptoms to having a 'permanent cold' ("I don't have a cold, but it feels like I have a cold", "you think you got a cold or something ... and it just doesn't go away"). Indeed a number of subjects felt that the onset of their symptoms related to a particularly bad cold or flu but, interestingly, colds and flus themselves seem to become much less frequent after the onset of their symptoms ("I never get colds anymore. That's one good thing about it - I never really get a cold", "When I was young I used to get a lot of colds, but I haven't for years").

Whilst popular perception may be that these patients are productive of great quantities of mucus, quite the opposite, in fact, seems to be true. Although patients complain of the sensation of an excess of phlegm, more in-depth questioning reveals that they frequently have very little to expectorate or blow out ("I feel like there is something at the back of my nose that I am trying to swallow and it dribbles. I never really can cough anything up", "there's nothing being coughed up", "that's very, very rare that that will happen, that it comes up"). Furthermore, given this lack of productiveness, some patients may even differentiate their sensation of excess mucus from what they consider to be 'real catarrh' ("[catarrh] is having a kind of mucus in your throat which you will probably cough up in the morning, probably related to smoking, like mucus that could be gotten rid of", "to me, [catarrh] means you bring up a lot of phlegm, like a bunged up nose that you can actually get clear, coming away, and phlegm coming up from the throat", "to me [catarrh] is like a green gunge that comes out").

Chronic catarrh, or post-nasal drip, also carries with it an emotional symptomatology. Many of the interviewees admitted to feeling disgusted by their problem and consequently found it socially embarrassing ("if you're in a crowded place and you've got to bring it up, you're conscious people can hear that and it can be very embarrassing. It is for the kids and for my wife", "it's not the nicest thing to talk about"). Additionally, the suggestion of *frustration* arose frequently within patients' narratives. When interviewees talked of their nose or throat sensation; two-thirds described their problem as "annoying", "an irritant" or "a frustration", either unprompted or when asked to sum up their problem with one word ("It's just annoying more than anything because you're always trying to get rid of it and it never goes", "it's a pretty constant irritation and you're just conscious of it.", "I mean when you speak to other people about catarrh, I think it is Table 1. List of standardised catarrh symptoms.

| Symptom | frequency |
|--|-----------|
| My nose is blocked | 38 |
| I feel secretions dripping down the back of my nose into my throat | 38 |
| I feel a constant need to clear my throat | 29 |
| I can't sleep because of my throat or nose symptoms | 26 |
| I have a dry tickly cough | 23 |
| I feel sick or retch due to the secretions in my throat | 22 |
| I have thick glue-like secretions which stick in my nose or throat | 20 |
| I get facial pain/pressure | 20 |
| I feel as if I am choking | 18 |
| I spit up phlegm | 16 |
| My ears feel blocked/full and/or I get buzzing in them | 16 |
| I feel a constant need to swallow | 14 |
| I have a sore throat | 14 |
| I feel the need to blow my nose but nothing comes out | 14 |
| I get a headache | 13 |
| I am unable to taste and/or smell | 12 |
| My nose runs | 12 |
| My throat feels dry | 12 |
| I get a foul taste or smell | 11 |
| I feel a lump on my throat | 10 |
| I get lumps or pains in my neck | 9 |
| My voice changes | 9 |
| I get heavy, swollen, sore or black eyes | 9 |
| I feel generally unwell, tired, or weak | 8 |
| Secretions gather in my throat and it feels like it's filling up | 8 |
| My breathing or my chest is affected | 8 |
| I have a dry/itchy nose | 8 |
| I get earache | 7 |
| I sneeze a lot | 7 |
| I have difficulty swallowing food | 7 |
| I have bad breath | 6 |
| I feel the need to sniff/snort | 4 |
| My mouth gets dry or sore | 4 |
| I get heartburn or an acid feeling in my gullet | 3 |
| I feel dizzy | 2 |
| I have a tickly throat | 2 |
| I get pus from my nose | 2 |
| I feel sad, depressed or irritable because of my symptoms | 2 |

Symptoms reported by catarrh patients in an open-ended questionnaire (n = 48). Symptoms reported by only one patient have been excluded.

considered as a damn nuisance."). This ties in well with the previous observation that for many chronic catarrh patients, theirs is not a problem of 'bringing up' too much phlegm but actually of having nothing to produce or clear.

DISCUSSION

In this study we have aimed to strip back the clinical problem that is chronic catarrh/post-nasal drip and we have looked to do this through the eyes of sufferers themselves. We are unaware of any previous studies doing this.

Our patient-derived symptom list is extensive and topographically varied. There are key symptoms that arise with a predictable degree of frequency viz. nasal blockage, postnasal secretions, need to clear throat, etc., but there are also other associated symptoms that emerge which might not normally be associated with catarrh by most clinicians e.g. heavy eyes, breathing problems and dry throat - each mentioned by at least 8 catarrh sufferers. Are these then simply 'symptom reporters' or is there a true link between these associated symptoms and the primary presenting complaint? Either way, it highlights the need for a comprehensive approach if a catarrh-specific outcome instrument was to be designed, rather than any pre-emptive physician-derived list. A case could certainly be made for such an instrument given that there are 15 symptoms on the catarrh list that would not be picked up even if all 3 of the most commonly utilised nose and throat instruments (Glasgow-Edinburgh Throat Scale, Reflux Symptom Index and Sinonasal Outcome Test) were applied (Table 2).

From this extensive symptom list, we can assume one of three conclusions. First, chronic catarrh is an umbrella term used loosely for a number of anatomically related problems e.g. rhinitis, globus pharyngeus, laryngopharyngeal reflux - but this seems unlikely in the face of normal investigations in catarrh chronic patients ⁽³⁾. Second, chronic catarrh may have a single trigger resulting a number of distinct nasopharyngeal sensations/experiences e.g. globus sensation, persistent cough, need to clear throat etc. Third, chronic catarrh may have a single trigger resulting in a universal experience that is simply being described using differing lexicon by different patients. Unfortunately, it is not feasible to distinguish between the latter two scenarios given the inherently subjective nature of chronic catarrh and the implicit reliance on patient narratives for data. We do know that chronic catarrh patients score as highly on symptom scoring instruments validated for globus pharyngeus, chronic rhinosinusitis and laryngopharyngeal reflux as do patients diagnosed with those respective conditions ⁽⁴⁾, but the above conclusions could equally be applied to these findings.

As said, there was a central core of symptoms that arose more frequently (largely pertaining to the nasopharynx) and those were the symptoms that patients focused upon when given the opportunity to do so during in-depth interview.

Table 2. Catarrh-specific symptoms.

| Summary of symptoms |
|---------------------|
| Blocked nose |
| Sick/retching |
| Spit phlegm |
| Headache |
| Loss of taste/smell |
| Dry throat |
| Bad taste/smell |
| Sore neck |
| Sore/heavy eyes |
| Throat filling up |
| Dry nose |
| Bad breath |
| Snorting |
| Dry mouth |

Symptoms reported by catarrh patients but not listed in either Glasgow-Edinburgh Throat Scale, Reflux Symptom Index or Sinonasal Outcome Test-20.

Key Quotation 1

"...it seems to me to be like having stuff in your nose that you blow out whereas here it's right at the back and it isn't coming - there's nothing being coughed up or... but it would be the kind of thing would expect to have if I... you know you hear of people having catarrh and coughing it up. I have that sensation without coughing anything up".

Male, 60 yrs

The picture painted then was of the sensation of a persistent cold that may or may not have started with true coryzal symptoms. Interestingly, and paradoxically, one of the overriding features of their problem was that they were unable to produce any real quantity of mucus or phlegm to account for their symptoms, as one would normally be able to with a viral cold. That is to say, it is not the frustration of having copious secretions to clear that bothers these patients, rather it is quite the opposite - it is the inability to clear anything out from the nose or throat which perpetuates the frustration that so many of them allude to. This is contrary to the current common conception that catarrh patients are perpetually expectorating or swallowing phlegm and, importantly, is counterintuitive to most of the first line medications used to try to relieve the symptoms of chronic catarrh viz. topical nasal steroids. Furthermore, another unexpected

finding regarding symptomatology that emerged from the interviews was that a proportion of interviewees did not consider themselves to be suffering from catarrh, *per se*. They did have a general consensus that catarrh implied a thick, often green, nasal discharge that could be spat out but that this was not what they had. This non-productive state would certainly better explain the lack of findings in the nose and throat on examination and clinical investigation ⁽³⁾ and further raises the likelihood that what many of these patients are experiencing is more a sensory dysfunction than a mucus over-production; why, if catarrh is truly due to mucus hypersecretion, should these patients not be able to expectorate it or blow it from their nose?

CONCLUSION

There is no universal symptomatology relating to catarrh. Catarrh patients describe a variety of symptoms from a variety of anatomical locations albeit centred around the upper aerodigestive tract. Difficulties exist in establishing whether this is a result of differing experiences or simply differing lexicon.

There is undeniably a cohort of patients with post-nasal drip who have a quantitative over-production of mucus e.g. patients with rhinitis, but such patients will invariably be able to recount expectorating or expelling this excess mucus. We would argue that these patients should be delineated from the significant proportion who present with an apparent post-nasal drip or persistent throat clearing but who admit to being unable to produce this phlegm. Investigations will invariably be unrevealing in such patients and nasal steroids and antihistamines are, perhaps more logically now, unlikely to be effective. Therefore their management ought be more focused on addressing their frustration and their embarrassment.

COMPARISON WITH LITERATURE

Monkhouse et al. ⁽²⁾ have previously published a list of symptoms from which catarrh patients (and non-catarrh patients) have selected those that they feel relate to chronic catarrh. However, this list was physician-derived and as such risks both prompting (patients may feel obliged to choose a selection of symptoms when presented with a list) and exclusivity (the list of symptoms is pre-emptive and patients do not have the option of offering their own symptoms). By offering an open questionnaire we have overcome both of these issues and so offer a more accurate reflection of the true catarrh experience.

The literature relating to postnasal drip and catarrh has, to date, primarily focused on attributing an organic cause for mucus hypersecretion ⁽⁶⁻⁹⁾. Our findings here, coupled with our earlier findings of normal rhinologic investigations in chronic catarrh patients, suggest that a move away from a pathophysiological explanation may now be appropriate.

STUDY STRENGTHS AND WEAKNESSES

In this study, a practicing clinician conducted the interviews. Although a doctor is in a privileged position of trust and confidentiality, which may reap relevant information that would not otherwise have been offered under interview to a non-medical researcher, there is equally the risk that the patients of a doctor researcher may offer - inadvertently or otherwise - replies which they feel the doctor wishes to hear. For this reason, it was made explicit to patients that their participation in the interview would not alter their clinical management in any way and that the researcher was not involved in any decision making regarding their care.

Whilst it is true that the cohort of patients presented to an ENT clinic will be selected from the larger number seen in primary care, it can be assumed - by virtue of them having been referred to secondary care - that these patients are presenting a clinical quandary in the primary care also.

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CONFLICTS OF INTEREST

The authors declare that there are no conflicts of interest to declare.

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