A PATIENT'S JOURNEY

Whooping cough

Ros Levenson

London

Correspondence to:

Ros Levenson

ros@roslevenson.demon.co.uk

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Recently I had whooping cough. This has now been confirmed by the results of a blood test. I was in little doubt about the diagnosis from the beginning. However, my experience suggests that, despite considerable literature on the prevalence of whooping cough in adults, the diagnosis is still not one that doctors readily think of when they are faced with an adult rather than an infant or child.

I can well understand why the general practitioners I saw in the first couple of weeks did not diagnose whooping cough at once. I am aware that the duration of the symptoms, as well as the nature of the symptoms themselves, is important, and there were more obvious diagnoses that sprang to mind. However, when I experienced the first two or three terrifying paroxysmal coughing sessions, I knew it was a cough unlike anything I had had previously and said so. It also reminded me of my daughter's whooping cough when she was a toddler, many years ago. I was also very struck by the information on the website of Dr Doug Jenkinson (www.whoopingcough.net), which gave descriptions that matched my symptoms exactly. As a result, I spoke to the general practitioner who had first seen me and asked if he thought it could possibly be whooping cough. I also asked another general practitioner whom I saw a week or so later. In both cases their answer was similar: it was unlikely to be whooping cough as it is rare in adults.

On a visit to a chest clinic soon after this, I again raised the possibility of whooping cough. Once more this was thought to be highly unlikely. It was only on my return visit, when I felt just about well enough to be a bit more assertive, that my repeated suspicion was acted on and blood was sent for testing. I think this happened partly because I provided the doctor with a copy of Dr Jenkinson's printout for doctors—a doctor to doctor communication always goes down best.

What are the lessons from my experience? Firstly, even allowing for the maxim, "If you hear hoof beats, think horses, not zebras" whooping cough in adults is actually not so rare. It is better described as under-diagnosed, rather than uncommon. Secondly, as an adult with a long history of asthma, I felt that it was automatically assumed that any respiratory illness must somehow be related to my asthma. Although this is understandable as the early days of my whooping cough were accompanied by a flare-up of asthma, I think it may have been a factor in doctors not being

sufficiently open to other, additional possibilities. Interestingly, the asthma nurse in general practice was not so sceptical of my self diagnosis. She agreed that whooping cough was relatively uncommon, but she accepted that that did not make it impossible. Significantly, I think she was also more attuned to believing that I knew and understood my own asthma, and if I said that this cough was different from all the other bouts of asthma and all the other chest infections I had ever had, then I was probably correct in my observation.

Would an earlier diagnosis have made any difference, given that no effective treatment is generally available? From a patient's perspective, I say that it would have been helpful, not least as I could have taken greater steps to avoid infecting others. Also, I inferred that I was heading towards a situation where invasive tests such as bronchoscopy were beginning to be considered—looking for something that wasn't there—rather than first considering less invasive testing for something that, as it turned out, was there.

From a personal point of view, it was interesting and salutary to be reminded how difficult it can be to have a sensible discussion about our own health at a time when we feel like crawling under the duvet and staying there. I work as an independent researcher and policy consultant on health service issues. I am also a non-executive director of an NHS trust. None of this counted for much when I had only enough energy to cough.

LEARNING ONLY HALF THE LESSON: A DOCTOR'S PERSPECTIVE

Taken at face value, this patient's account invites clinicians to consider two main possible learning points. One relates to the relatively simple matter of updating biomedical knowledge, and the other concerns the generic application of clinical method.

These clinicians were sceptical of whooping cough as an explanation for her cough, probably because of its apparent rarity in immunised adults. However, not only is evidence growing about the higher than expected incidence of whooping cough in adults, but the protection offered by most immunisation schedules wanes over time in many individuals.

Interestingly, the patient is more forgiving of the clinicians' gaps in technical knowledge than of their not taking seriously her ideas about her illness.

The development of the patient centred clinical method had its origins in the analysis of the process and outcome of consultations in general practice. Pioneering general practitioners found that eliciting and responding appropriately to patients' agendas was associated with consultations going well. An explicit patient centred clinical method evolved, and evaluative studies generally indicate better outcomes when principles of patient centred communication are applied in consultations. Litigation and complaints, too, are far less common when patients feel listened to. Two of the six components of the patient centred consultation are exploring patients' expectations, feelings, and fears about their symptoms, and finding common ground with them about management.

The biggest problem here was that the clinicians apparently did not ask the patient about her own pretty expert ideas about her symptoms, and when she insisted they listen to her concerns, they failed to find common ground with her about management. Although politely handled, the consultations might have been caricatures of the biomedical model of clinical practice, where the

"doctor expert" asks mainly closed questions, makes an assessment, and then tells the patient what is wrong and what should be done. The potential benefits to the therapeutic process from harnessing the patient's considerable expertise were therefore lost.

Would the hard outcomes have been different if the patient centred clinical method had been applied in the context of disease specific technical excellence? A "superdoc" might have begun by asking an open question about the patient's cough—it would have emerged that this cough was strikingly different from her "asthma cough." A natural next question would have been, "So what do you think might be causing it?" Her thoughts and experience about whooping cough would have emerged, and a description of the cough, or even observing it, would have confirmed the diagnosis then and there, without even a blood test. Sharing the evidence about the futility of antibiotic treatment and the natural course of the illness and tackling concerns about transmission would have saved referral and laboratory costs and allowed the patient to await recovery with her anxiety largely contained.

The positive, from the patient's perspective, is that both the generalist and specialist clinicians recognised they had lessons to learn. They planned to get up to speed with the rapidly changing evidence base about whooping cough in adults and share their new knowledge with colleagues. But unless lessons are learnt beyond disease specific technical excellence to include the generic application of the patient centred clinical method, these clinicians will again soon be shooting themselves in the foot, albeit in another disease area.

Christopher C Butler professor, Department of Primary Care and Public Health, Cardiff University, School of Medicine, Neuadd Meirionnydd, Heath Park, Cardiff CF14 4XN butlercc@Cardiff.ac.uk

The good news is that when whooping cough was finally diagnosed, the consultant kindly said that it was a "learning point" for chest physicians in the hospital. In primary care the practice nurse asked if she could discuss my experience at a practice meeting where they considered how they could do things better and differently. Since no one can be expected to get it right all of the time, I guess that's about as good as it gets,

and I appreciated their humility. I also hope that my experience, and theirs, will make it less likely that quite so many other cases of whooping cough in adults will be missed.

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A memorable meeting: 100 years ago?

I was an anonymous senior house officer in obstetrics and gynaecology at the time. I had ended up in a tertiary referral centre while trying to get some experience relevant to general practice.

There were regular meetings at 8 am for the junior staff, and I was horrified when I realised that I, too, had been included on the meeting schedule. The remit seemed vague, no one had asked or suggested what I might want to present. Just in time, something occurred to me that I thought was interesting.

The morning arrived, and I nervously read out my handwritten overhead projection slides. During and after my presentation there was complete silence. There were no questions and no comments. The rest

of the department filed out of the door, presumably relieved it was over. The subject? A patient's perspective of a late diagnosis of ectopic pregnancy. The patient was my cousin, and she had kept notes throughout her ordeal. The experience had been traumatic for her.

The *BMJ* now regularly publishes patients' perspectives of their health and illnesses. I wonder if the obstetric and gynaecology department's reception of my presentation would be more active now. After all, it was not 100 years ago, only 10.

Claudia Hanso GP locum registered with Lambeth Primary Care Trust, Tallinn, Estonia claudiahanso@hotmail.com