Unwrapping the diagnosis of tuberculosis in primary care:

a qualitative study

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ABSTRACT

Background

Although tuberculosis (TB) is relatively rare in the UK, its diagnosis is important because diagnostic delays can result in worse outcomes for patients and expose others to the risk of infection. Atypical presentations may be common, and patients' help-seeking behaviour may influence the diagnostic process in primary care. Little is known about the process of diagnosing TB in primary care in developed countries.

Aim

To understand the process of diagnosing TB in UK primary care.

Design of study

Qualitative inductive study with paired semi-structured interviews.

Setting

Communities and general practices in south-east Wales.

Method

Interviews were conducted with 17 patients diagnosed with TB in the previous 6 months and 16 GPs involved with their care. Data were analysed thematically.

Results

In response to expected classical features, GPs generally ordered specific tests. Both GPs and patients reported atypical presentations, and then the diagnostic and referral net was appropriately widened in most cases. Identified barriers to prompt diagnosis included atypical presentations and low clinical suspicion of TB, lack of continuity of care, workload demands that limit time with patients, and suboptimal clinician–patient communication. GPs recognised the growing problem of TB nationally and the need for improved education among health professionals.

Conclusion

GPs' and patients' accounts about the process of diagnosing TB suggest that delays can occur, although they are not typical. Where diagnosis is clear, GPs generally test specifically and refer appropriately; where diagnosis is less clear, the diagnostic net is cast further. It is only when certain core values of general practice are not applied (including continuity of care, considering context appropriately, and eliciting and responding appropriately to patients' explanatory models) that clinicians and patients identify a suboptimal diagnostic process.

Keywords

diagnosis; presentation; primary care; qualitative; tuberculosis.

INTRODUCTION

In 1993 the World Health Organisation (WHO) declared tuberculosis (TB) a global emergency, estimating that approximately a third of the world's population was infected with *Mycobacterium tuberculosis*.¹ TB is also on the rise in the UK.²³ Of the 178 cases notified in 2004 in Wales, 41.6% occurred in south-east Wales.⁴ By comparison only 150 cases of meningococcal disease, a disease with a high public, research, and clinical profile, were notified in Wales in the same year.⁵ Left untreated, a person with infectious pulmonary TB may infect a further 10–15 people each year.⁵

Lack of awareness of TB is thought to contribute to problems with control in times when TB might wrongly be considered a rarity.^{7,8} Changes in the management of TB may have altered public and professional attitudes to an important disease (Box 1).

Box 2 summarises the traditional risk factors and presentation of TB. However, there are an important, and possibly growing, number of cases that do not fall into these categories. Case reports globally have highlighted a diversity of presentations, particularly in the young or those also infected with HIV.⁹

Little is known about diagnosing TB in modernday general practice in developed countries. A better understanding of the processes of diagnosis could highlight existing good practice and opportunities for enhanced care. The aim of this

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study was to examine clinicians' and patients' perspectives on the process of diagnosing TB in general practice.

METHOD

Settina

The study was conducted within the former boundaries of Bro Taf Health Authority, South East Wales, chosen because of the breadth of its sociodemographic and geographical characteristics. It included a major city (Cardiff) and surrounding rural and post-industrial areas.

Participants

Patients recently diagnosed with TB were identified by specialist TB nurses at three hospitals during 2003. Patients presenting via Port Health Authorities and those receiving chemoprophylaxis were excluded, as the study sought to explore clinical decision-making surrounding the diagnosis of TB in primary care.

The specialist nurses approached patients with an information leaflet about the study. Patients who agreed to take part were then contacted by the study team. Written consent was obtained by the researcher before the interview commenced. Nurses were encouraged to make a special effort to recruit participants with a range of ages, ethnic origins, and place of abode (urban, rural, and post-industrial). This was monitored as the study progressed.

With each patient's consent, their GPs were sent a 'doctor information sheet' describing the study. They were subsequently contacted by telephone to arrange an interview.

Interview procedure

Semi-structured interviews were conducted with patients by one author. Patients gave an account of their health during the period preceding diagnosis, their contact with health services, and their views about TB and the diagnosis. Interviews lasted approximately 45 minutes.

Having a first language that was not English was not an exclusion criterion. Arrangements were made for interviews to be conducted with the aid of an interpreter for participants whose first language was not English; however, all participants were able and willing to conduct the interview in English. Questions were mainly open ended with clarification of detail given as required.

GPs were also interviewed, using a semistructured interview guide, by one of two authors. GPs were asked to provide an account of the diagnostic process of their patients' specific cases (referring to case notes as required) as well as to reflect on TB more generally.

How this fits in

TB is a growing problem in the UK which frequently presents atypically; delayed diagnosis leads to increased morbidity and spread. Barriers to prompt diagnosis of TB include atypical presentations, as well as low clinical suspicion of TB, a lack of continuity of patient care, limited time with patients due to heavy workload, and suboptimal communication between the doctor and patient. The primary healthcare system in the study area appears to be performing reasonably well in relation to TB diagnosis, but delays in diagnosis occur when certain core values of primary care are not applied.

Box 1. Changing approaches to TB management in the UK.

- Mass miniature radiography discontinued in the 1950s.
- Temporary cessation of the BCG (Bacille Calmette-Guérin) vaccination programme due to a vaccine shortage. Shift to targeted vaccination of high-risk individuals only, commencing September 2005.
- ▶ In 2004 the Chief Medical Officer, Sir Liam Donaldson, announced a need to 'get back to basics', claiming that too many health professionals think tuberculosis has disappeared in Britain.⁶

The interview process was iterative and interview guides were refined as data collection progressed. Interviews were audiotaped and transcribed, except in one case where notes were taken because the GP preferred not to be recorded.

Analysis

Interviews were analysed thematically, facilitated by NUD*IST software. The research team identified categories of data; data were coded into these

Box 2. Risk factors and presenting symptoms of TB.

► Risk factors for TB in the UK:10

Immuno-compromised, including HIV

Chronic alcoholism

Drug misuse

Young age/old age

Minority ethnic groups/immigrants and those travelling from high incidence areas

► Traditional presenting symptoms:¹¹

Persistent cough

Haemoptysis

Night sweats or fever

Weight loss

Chest-wall pain

Non-resolving pneumonia

Dyspnoea.

Table 1. Participants' demographics.

Patients	GPs	
(n = 17)	(n = 16)	
Age range, years	19–80	30–66
Sex		
Male	11	12
Female	6	4
Self-defined ethnicity		
Caucasian	9	13
Non-Caucasian	8	3

Table 2. Symptoms reported by GPs and patients.

Number reported

	Number reported	
Symptom	GPs	Patients
Persistent cough	12	11
Weight loss	8	12
Fatigue	6	14
Dyspnoea	4	5
Sore throat/hoarse	4	2
Loss of appetite	4	11
Personal neglect	4	2
Headaches	3	1
Fever	3	9
Haemoptysis	2	3
Effusion on lung	2	0
Abdominal pain	2	1
Coloured sputum	2	2
Depression	2	3
Diarrhoea	1	0
Nausea	1	2
Chest wall pain	1	0
Sweats	1	9
Polyuria	1	0
Joint pain	1	2
Anaemic	1	1
Thirst	1	1
Constipation	1	0
Slow recovery after operation	1	0
Lump on body	1	2
Rash	1	0
Back/limb pain	0	5
Sleep disturbance	0	4
Skin colour/pallor change	0	3
Clear sputum	0	2
Cold extremities	0	2
Alcohol intolerance	0	2
Dark urine	0	1
Photophobia	0	1
Dizziness	0	1

categories as were gathered by two researchers. The process continued until categories were saturated. Categories were merged into themes. ¹² Each interview was independently read by all team members. Ambiguities and disagreements about coding were resolved, where necessary, by discussion among all researchers.

RESULTS

Participants

Eighteen patients agreed that the TB nurses could pass on their names to the study team, but one subsequently declined to participate due to lack of time. The remaining 17 provided written consent and were interviewed. About 75 cases of TB were notified in the study area during 2003, but it is not known exactly how many patients were originally approached by the specialist nurses to participate or how many of those were 'port-of-entry' diagnoses.

Sixteen GPs were approached and agreed to participate. The GP of the 17th patient could not be contacted as the practice was outside the area covered by the study's ethics approval. The patient had moved into the study area during the early stages of treatment. Table 1 summarises the demographic characteristics of responders.

Patterns of presentation

Presenting symptoms. Fourteen of the 17 patients were diagnosed with pulmonary TB. Non-pulmonary cases were TB of the shoulder, TB of the larynx, and TB meningitis.

Many classical symptoms were reported by GPs, with persistent cough and weight loss being the most common (Table 2). See Box 3 for an example of a typical case presentation. Fatigue, sore throat, and reduced appetite were also commonly reported and fall outside the classical presentation of TB.

Similar to the GPs' reports, symptoms most commonly reported by patients were fatigue, cough, and weight loss (Table 2). However, fever, sweats, and appetite loss were more common when compared with GPs' accounts. Symptoms that were only reported by patients include back and limb pain (n = 5), sleep disturbance (n = 4), skin colour/pallor change (n = 3), and alcohol intolerance (n = 2).

Health-service interaction. Nine GPs reported that the diagnosis of TB was unexpected, given their patient's general health, medical and social history, and presenting symptoms. One patient (an international student new to the country) was not registered with a GP and was taken to an accident and emergency department (A&E) by friends following haemoptysis.

Three patients presented to the GP only once during the illness episode, prior to diagnosis. The majority of the sample made two, three, or four visits, presenting with a variety of symptoms. The patient with TB of the shoulder presented six times over the course of a year and the patient with TB meningitis made four visits to her GP, and presented to A&E three times. Generally, patients did not find it difficult to access their GP and were often seen within a few days, although some patients reported reluctance in presenting and attending for investigations because they were scared, in fear of wasting medical time, or in denial of possible diagnoses.

Diagnostic processes employed

History, examination, and investigation. Clinical alerts, such as traditional symptoms or risk factors, raised GPs' indices of suspicion but often the examination was unremarkable. In addition to clinical signs and symptoms, GPs drew on their knowledge of the social circumstances of their patients, for example housing conditions, country of origin, occupation, drug misuse, and recent foreign travel. Over-reliance on such cues sometimes meant that GPs might have delayed diagnosis in cases where poor living conditions were not an issue:

Researcher: 'Apart from having co-existing lung disease is there anything you think puts her in a high-risk group?'

GP 12: 'No, I would very, very much doubt. I don't think she is any more involved in alcohol than any other teenager. Delightful little house, plenty of dogs and things. The last time I saw her she was shopping in Tesco. Its probably not a thing I would suspect unless [it was] somebody with a persisting cough, losing weight, known to have poor eating habits, poor social circumstances, occasionally sleeping rough or neglect, and of course haemoptysis.'

Investigations commonly undertaken when TB was suspected included X-rays, and blood and sputum tests. A wider range of tests were ordered in cases with less traditional features, for example, markers of inflammation. GPs reported that this approach provided a diagnostic 'safety net' where, although they may not have clinically suspected TB, the range of investigations would generally alert clinicians to unusual but serious diagnoses. Therefore, TB was often diagnosed as a result of casting a wide net of investigations, as opposed to clinically suspecting TB and ordering a narrow range of relevant tests.

Box 3. Typical case presentation.

Patient 10 was a Caucasian man in his 60s living in sheltered accommodation with a history of alcoholism, smoking, asthma, mental illness, personal neglect, and bursitis. He did not present at the surgery, instead his carer requested a home visit after noting a decline in his health and behaviour, which included staying in bed, not eating, weight loss, and weakness.

He was not a frequent attender at the surgery having last been seen a year previously for a severe chest infection. An X-ray done at that time was reported as normal. On seeing him at home, the GP noted he was cachexic, coughing, breathless, and had crackles on auscultation. The GP sent him for an X-ray (accompanied by his carers to ensure he would go), querying TB and lung cancer due to his smoking. The chest X-ray suggested TB and that cancer should be excluded. He was admitted urgently to hospital. At interview the patient reported that he also had been coughing up grey phlegm and had distaste for alcohol. The patient had considered he might have lung cancer.

In cases where there was still uncertainty about the diagnosis, GPs referred patients to secondary care for their opinion:

"Recurrent sore throat, persistent hoarse voice, no problems with swallowing etc, uh, nothing to find on examination, refer ENT". Um so that's how it was picked up. The ENT surgeon thought there was something abnormal on his vocal cord so it was biopsied and it revealed TB.' (GP 4, reading from notes)

Differential diagnoses. GPs proposed differential diagnoses that included, in order of frequency, malignancies; lower respiratory tract infection; asthma; chronic obstructive pulmonary disease; pneumothorax; pulmonary embolus; diabetes; depression; viral illness; malaria; and arthritis. As one GP commented:

'He could have just had a very bad depression. [He] just stopped eating and [had] taken to his bed.' (GP 10)

Most GPs had a relatively low index of suspicion for TB, except in classical presentations, or as the presentation of an unusual case evolved:

'It would be very low down on the list ... you tend to think more of a cancerous process.' (GP 2)

Patients and their relatives also considered a wide range of diagnoses. Three considered TB, but the majority suspected alternative explanations

Box 4. Presentation with few traditional symptoms.

Patient 3, a white European in his 50s, had had a suspicious chest X-ray as a child, for which he did not undergo any treatment. His aunt had TB of the spine 50 years previously. He presented six times in the year before diagnosis, to both the GP and accident and emergency department. He gave a 10-year history of pain and reduced range of movement of his shoulder. Initially he was diagnosed as having arthritis, and was treated with steroid joint injection, and painkillers. Having failed to respond, he was referred for a shoulder X-ray and was also found to have raised inflammatory markers. He was eventually referred to an orthopaedic surgeon who aspirated the joint, and TB was diagnosed by culture of the aspirate. In retrospect, it was felt by the patient's GP that this diagnosis might still have been missed, due to the unusual presentation.

including cancer⁵, infection,⁸ and depression:²

'I thought it was normal fever over the days. Then it was night fevers, losing my weight, and sort of malaria or anything. I hadn't thought of this thing TB.' (Patient 15)

The wide differential diagnosis was reflected in the spectrum of treatments initiated by patients or their doctors. These included antibiotics most

Box 5. Presentation with few traditional symptoms.

Patient 16, of Asian origin, presented to her GP four times, and to accident and emergency (A&E) three times before a diagnosis of TB meningitis was made. She reported visiting her GP with a 10-day history of headache, neck discomfort, photophobia, and non-specific flu-like symptoms, including a dry cough. She recalled raising her concerns that she might have meningitis. She stated that her GP initially reassured her that these concerns were unfounded and a diagnosis of upper respiratory tract infection was made.

She was seen again the following day by the same GP who ordered a chest X-ray and blood tests. The patient presented on two further occasions in general practice. A different GP prescribed antibiotics and an out-of-hours doctor diagnosed respiratory infection. She failed to improve, and was finally admitted on her third presentation to A&E. TB meningitis was considered, despite a normal CT scan of the head and negative cerebrospinal fluid cultures. TB treatment was commenced and she responded well.

On reflection, the GP interviewed felt they probably would not have acted differently, having considered her concerns about TB, and by arranging preliminary investigation. Blood tests were normal, but the patient was admitted via A&E before the chest X-ray could be followed up.

commonly, and over-the-counter preparations such as paracetamol.

Barriers to the diagnosis of TB

Atypical presentations and low clinical suspicion of TB. GPs felt more confident diagnosing TB when it presented classically. However, their clinical suspicion of TB was low if there were few traditional symptoms or risk factors and thus, diagnosis was more difficult (Boxes 4, 5 and 6). This was amplified by their reported lack of recent knowledge about TB, due to insufficient training. More recent knowledge arose from the medical press, the internet, the popular press, and television. Many expressed concerns that medical education about TB was lacking:

'There haven't been any sessions to inform us about TB ... TB is not one of those that's on the agenda.' (GP 1)

Some GPs thought that TB presentation might be changing, with non-pulmonary presentations becoming increasingly common. Although the majority of GPs were aware of local specialist services, detailed knowledge of these services was lacking. Particular confusion surrounded the current status of the Bacille Calmette-Guérin (BCG) immunisation programme.

Lack of continuity of patient care. In some cases, continuity of care was suboptimal, with patients being seen by a number of different doctors, from general practice and secondary care, before the diagnosis of TB was made. When questioned about potential barriers to diagnosing TB, this issue was raised by patients and GPs:

'I understand how busy the doctors are especially when you've got one doctor off on holiday, got locums covering and that and I really do understand that.' (Patient 8)

'The second thing that went wrong is that she presented to A&E and it was taken out of my hands.' (GP 11)

'You've got different doctors seeing her all the time.' (GP 8)

As a further example, one GP discussed how a patient had moved from London, after having already had some investigations undertaken. The GP had felt frustrated by the lack of information from the previous medical team involved in the patient's care.

Workload demands limiting time with patients. A

minority of GPs suggested increasing workload as a possible factor in delaying the diagnosis of TB, as they might simply have been too busy to consider more unusual diagnoses:

'Everybody today is so busy, and so many things the GP does, and they are bogged down as you appreciate with the paperwork, so much goes on.' (GP 5)

Suboptimal clinician-patient communication. On the basis of GP and patient interviews, patients' beliefs also appeared to be a significant barrier to diagnosis:

'First she wanted me to go to the outpatients for an X-ray. I didn't. I suppose I was afraid.' (Patient 6)

Patient health beliefs also led to withholding information, delayed presentation, and lack of compliance with investigations.

Although three patients considered TB themselves, no patient reported being asked by GPs what they thought was causing their symptoms. Two patients suggested the possibility of TB to their GPs; their suggestions were apparently rejected. In one case, the patient had to persuade the GP to investigate for TB. Only three patients were critical of the delays in diagnosis:

'A chest X-ray should have been offered the second time or at least the third.' (Patient 8)

Researcher: 'What prompted you to go to A&E rather than back to your doctor?'

Patient 16: 'Because I wasn't having much done by my doctor. Sort of saying it's nothing, it's flu, but I knew there was something wrong.'

'I goes to him, "I think I got TB," and he goes, "that is not true". I said, "I think it is going to be true" and he goes to me, "well, we are going to take you to X-ray."' (Patient 13)

Current good practice

GPs reflected that a relatively prompt diagnosis was assisted by responding to patients' concerns and expectations, and effective communication between healthcare professionals in conjunction with good note keeping, computerisation, coding of diagnoses, summarising, and follow-up systems which aided continuity:

'I don't think anyone of us here thought about it

Box 6. Presentation with few traditional symptoms.

Patient 8, a white European, presented six times to her GP practice over a period of 5 months and saw three different GPs. She was generally in good health, although a smoker. Her initial symptom was a dry, chesty cough, which she first thought was due to a pollen allergy. After some weeks she developed breathlessness and presented to her GP who diagnosed a chest infection and prescribed antibiotics, which provided some relief. She also took paracetamol and a cough mixture.

She presented again when she became more unwell (tiredness, poor sleeping, weight loss) and was prescribed two more courses of antibiotics. When she presented with pleuritic chest pain, a locum GP requested a chest X-ray as he was concerned about a possible diagnosis of lung cancer. The X-ray indicated a pleural effusion and sputum was sent for AFBs (Acid Fast Bacilli) at which point TB was diagnosed and she was admitted to hospital.

The GP reported that on reflection, the patient might have been referred sooner, and suggested that delay could have arisen due to different approaches by different GPs.

but nevertheless the correct procedures were in place so that the diagnosis was made.' (GP 4)

DISCUSSION

Summary of main findings

This is the first study to use qualitative methods to explore the process of diagnosing TB in primary care in a developed country. These accounts from patients and GPs about the diagnosis of TB suggest that, although delays occur, this is not typical.

Where diagnosis is clear and patients present with symptoms that (at least in theory) have higher predictive values for TB, GPs generally test specifically and refer appropriately. Where diagnosis is less clear and patients present with more vague symptoms that have a lower predictive value, the diagnostic net must be cast further. It is only when certain core values of general practice are not applied — for example continuity of care; considering context appropriately; and eliciting and responding to patient ideas, concerns, and expectations¹³ — that clinicians and patients identify a suboptimal diagnostic process.

This study has highlighted the breadth of presentations and challenges met by GPs in making a timely diagnosis of TB. GPs successfully diagnosed TB when it presents in its 'classical' form. However, too great a reliance could be placed upon an expectation that TB will present in its 'classical' form, particularly when working under pressure with time constraints. GPs acknowledged the need to raise both their currently low clinical suspicion of TB and their awareness of atypical presentations.

Investigations were sometimes used as a 'safety net','4 aiding the identification of cases when TB was not clinically suspected. Where there were delays in diagnosis, these were sometimes patient-related due to lack of awareness and denial, and sometimes GP-related due to low awareness, low index of suspicion, and lack of continuity of care.

Strengths and limitations of the study

Although patients with TB might be considered difficult to access, all patients but one who originally expressed an interest in the study were successfully interviewed. There is, a possibility that additional data would have been obtained from participants in other geographical locations or risk groups that the authors were unable to access, such as children and intravenous drug users.

The patient sample was derived from participants who were willing to participate in the study identified by TB nurse specialists. As such, it may have been more likely that patients with positive experiences or strong views were interviewed. Alternatively, more of those dissatisfied with the process may have volunteered as an opportunity to express their concerns.

Comparison with existing literature

The databases of Medline, PubMed, and EMBASE were searched for the years between 1966 and 2005, using the terms 'tuberculosis' and 'diagnosis'; no study exploring the process of diagnosing TB in primary care in developed countries was found.

Several papers demonstrated that missed diagnoses and delayed treatment are associated with increased morbidity and mortality. 15-17 Previous studies describing the processes of TB diagnosis have centred on hospitalised patients in developing countries. 18-20

Implications for future research and clinical practice

Core values of general practice include continuity of patient care, considering context appropriately, and eliciting patients' explanatory models and responding appropriately. Most of these accounts provide examples where the process of diagnosing TB in primary care was satisfactory. An unsatisfactory diagnostic process was associated with poor application of one of these core values. Therefore, these accounts support the application of the values that underpin the discipline of general practice.

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Competing interests

The authors have stated that there are none

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